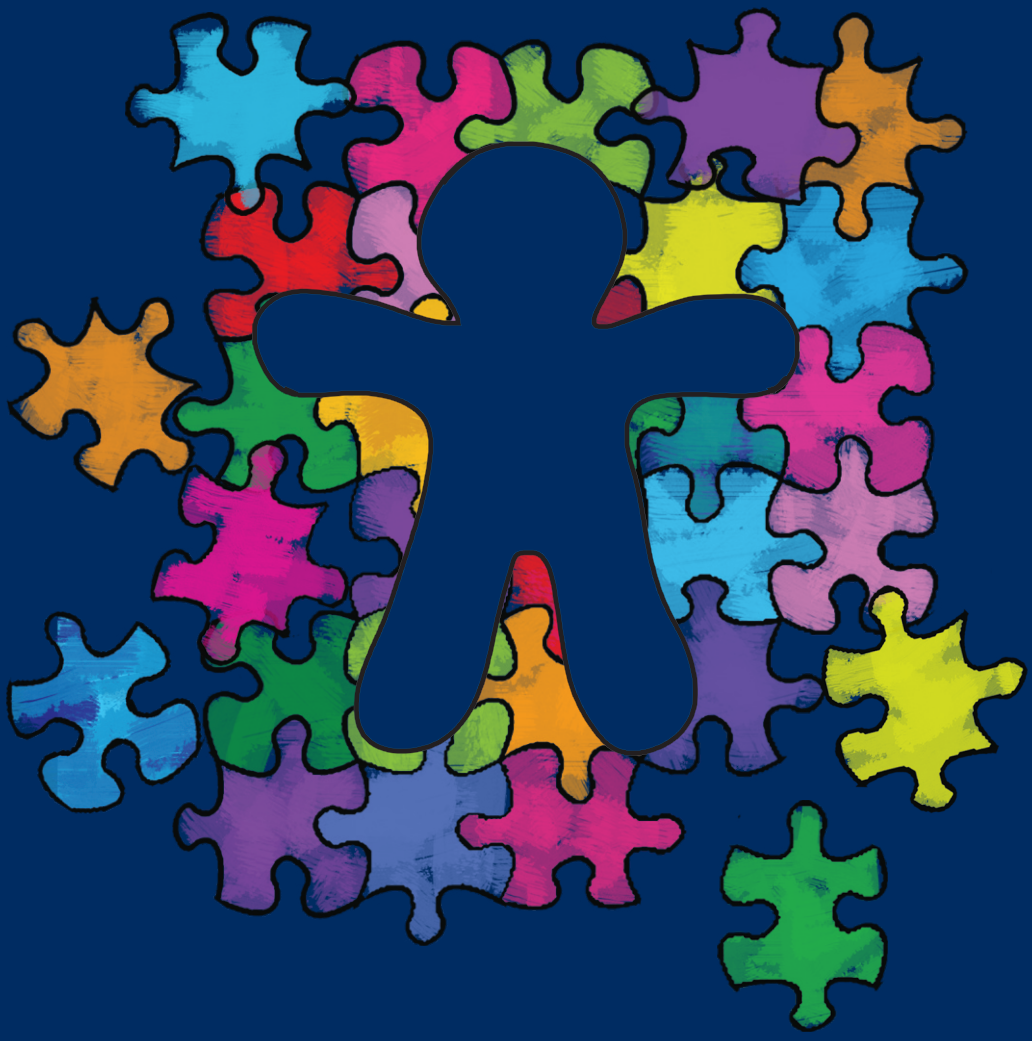
CROSSING BOUNDARIES

IMPROVING COMMUNICATION IN CEREBRAL PALSY CARE



JITSKE GULMANS

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IMPROVING COMMUNICATION IN CEREBRAL PALSY CARE

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‘We can make life miserable or wonderful for ourselves and others depending upon how we think and communicate’

Marshall Rosenberg, PhD

CONTENTS

CHAPTER 1

GENERAL INTRODUCTION

Background

Cerebral palsy (CP) is one of the most severe chronic disabilities in childhood, often making strong demands on health, education and social services as well as on families and children themselves [1]. In the Netherlands, children with cerebral palsy are the largest diagnostic group treated in paediatric rehabilitation [2], with a prevalence ranging from 1.5 to 2.5 per 1000 live births with little or no variation among western nations [3, 4]. CP has usually been defined as an umbrella term covering a group of motor disorders caused by a non-progressive lesion of the immature brain [5]. More recently, activity limitation was added as conditional feature and an annotation was made that the motor disorders are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems [6].

As no two children are affected in the same way, individual treatment programs vary widely, presenting care providers with heterogeneous and complex diagnostic and therapeutic challenges, requiring a broad range of specialized services from various professionals across diverse institutions and settings [7]. One of the major challenges in such interdisciplinary and -organizational settings is to provide 'integrated care', which generally refers to 'a set of coherent and coordinated services which are planned, managed and delivered to patients across a range of organizations and by a range of cooperating professionals and informal carers' [8]. The main aim of these efforts is 'to enhance quality of care and quality of life, consumer satisfaction and system efficiency for patients with complex, long term problems cutting across multiple services, providers and settings' [9]. In the US, the provision of integrated care for children with special health care needs (CSHCN) is stimulated through the 'medical home' concept [10, 11]. Also in the Netherlands, integration of paediatric services across diverse institutions and settings is high on the agenda, emphasizing the need to cross organizational boundaries and cooperate in inter-organizational networks or care chains [12, 13].

Despite this emphasis on care coordination and integration, this is becoming increasingly difficult to realize due to the growing complexity of health care, which is characterized by 'more to know, more to do, more to manage, more to watch, and more people involved than ever before' [14]. Particularly in the rapidly increasing population of chronic patients with more than one condition, health care organizations often operate as silos, providing care without complete information about the patient's condition, medical history or services provided in other settings [14].

In their report 'Crossing the Quality Chasm', the Institute of Medicine formulated six aims for improvement, stating that health care should be safe, timely, effective, efficient, equitable, and patient-centered [14]. With respect to this latter aim, care coordination and integration is specified as one of the key features to ensure that accurate and timely information reaches those who need it at the appropriate time [14]. Consequently, effective communication within the health care system and between the health care system and the larger community is of utmost importance [15]. Especially in the care of children with complex chronic health conditions, effective communication among providers involved was found to be a fundamental feature in parents' experiencing services as connected or coordinated [16].

In practice though, inadequate communication among health care providers and organizations involved in the child's care is one of the main barriers that challenge care coordination in paediatric services [17]. Based on data of the U.S. National CSHCN Survey [18], a study among CSHCN populations with neurological conditions found that children with multiple conditions had the greatest unmet needs and dissatisfaction with care coordination, which was defined in terms of communication among doctors and between doctors and other providers and whether the family received sufficient help coordinating care, if needed [19]. In the Netherlands, the importance of effective paediatric care communication has also been widely recognized, and as a result all rehabilitation services use the same instrument, the Rehabilitation Activities Profile for Children (Children's RAP [20]), which provides guidelines on how to formulate children's needs, define service goals and develop customized coordinated care programs. Although this instrument is the benchmark for formulating interdisciplinary paediatric treatment plans and as such crucial for communication among various professionals and parents [21], its scope is limited to the rehabilitation setting, while paediatric services often cross various other settings as well, including hospital care, primary care, (special) education/ day care as well as diverse community services. While for the youngest children various cooperation initiatives across these settings are currently being developed [22, 23], such efforts are still largely lacking for other age categories [13]. This is also reflected in a descriptive quality inventory on cerebral palsy care in The Netherlands [24], which identified the need to strengthen the care network and improve patient care communication across organizations and settings. In line with this, one of the main innovation themes identified by the Dutch Advisory Committee in Paediatric Rehabilitation is to improve paediatric communication and collaboration and create integrated networks across organizational boundaries [12].

Objective and proposed research directions

The aim of this thesis was to contribute to the improvement of patient care communication across the integrated care setting of cerebral palsy in the Netherlands. For this purpose, two subsequent phases have been followed. In the first phase of the study, the focus was on identifying experienced gaps in parent-professional and inter-professional communication across the cerebral palsy care setting in three Dutch care regions. These gaps formed the basis for the second phase of the study, in which the focus was on obtaining insight in the feasibility and usability of an eHealth application as a potential improvement strategy for patient care communication in each of the three care regions.

Evaluating patient care communication across integrated care settings

Among the broad research area of health communication, the study of patient care communication across integrated care settings such as cerebral palsy can be positioned in the field of 'organizational health communication' [25], which examines 'the use of communication to coordinate interdependent groups, mobilize different specialists and share relevant health information within complex health care delivery systems to enable effective multidisciplinary provision of health care and prevention of relevant health risks' [25](p. 264). This definition points out the importance of studying communication in health care delivery systems in order to change these systems to better meet patients' needs. This corresponds with the tenets of the Chronic Care Model [26], which is based on the premise that good health care outcomes result from 'productive interactions' between informed, activated patients (and families) and prepared, proactive practice teams [27, 28].

However, appropriate research methodology to evaluate patient care communication across diverse organizational settings is lacking. Existing methods are often restricted to only one aspect of communication (e.g. discharge- or referral communication), one communication link (e.g. general practitioner–hospital specialist) or one evaluation perspective (e.g. the perspective of primary care physicians), or rely solely on quantitative- respectively qualitative methods, thus obtaining either general/ population based data or in-depth qualitative data derived from small samples [29]. In view of these shortcomings, we developed an evaluation approach based on a sequential mixed method design [30] applying a framework with aspects essential for integrated care, including key elements of the Chronic Care Model [26, 28, 31], quality of care aspects formulated by the Institute of Medicine [14] and essential quality dimensions of information (-exchange) [32]. In the first part of this thesis we describe the development of this approach as well as its subsequent application in the integrated care setting of cerebral palsy in three Dutch care regions.

Potential of eHealth applications to improve paediatric communication

In the context of the growing complexity of health care systems, the importance of effective use of information and communication technologies (ICT) to provide integrated care across patient conditions, services and sites is widely emphasized [14, 33, 34]. The application of ICT to improve health system performance is generally indicated through the term 'eHealth' [35], which can be defined as 'an emerging field in the intersection of medical informatics, public health and business, referring to health services and information delivered or enhanced through the Internet and related technologies' [36]. Although much has been written about its potential to enhance access to care and increase efficiency, eHealth applications in paediatric care settings have been relatively scarce [37]. More recently however, they are increasingly used and studied for its potential role in health care delivery for paediatric patients [38, 39]. In the care of children with special health care needs (CSHCN), eHealth applications are predominantly synchronous ('real time'), with video-conferencing as the most common mode of communication, and consultation and diagnosis as the most common function [38]. In order to realize coordination and integration of care, the use of asynchronous ('store and forward') applications that span the whole care network is of vital importance, though as yet underexposed in CSHCN patient populations such as cerebral palsy.

Hereto, we developed an asynchronous web-based system aimed to improve patient care communication across the cerebral palsy care setting. In the second part of this thesis, we describe its development and pilot-evaluation in each of the three care regions. Representing an 'innovator' phase [40, 41], early prototypes of eHealth technology are generally evaluated on technical stability and user acceptance [42, 43]. Therefore, our primary focus was on obtaining insight in the system's feasibility and usability in the cerebral palsy care setting, both from the perspective of parents as well as involved professionals. Based on relevant frameworks of usage intention and subsequent usage behaviour [44, 45], we aimed to get insight in determinants of system use and non-use, in order to specify potential directions for further development and diffusion of this eHealth service in integrated care settings such as cerebral palsy.

Outline of thesis

The first part of this thesis is focused on identifying experienced gaps in patient care communication across the integrated care setting of cerebral palsy in three Dutch care regions. Hereto, we developed a mixed method evaluation approach, which incorporated an operationalization of patient care communication attuned to integrated care settings and takes into account the various communication links and evaluation perspectives inherent to these settings. In Chapter 2 we describe this approach, using the cerebral palsy care setting as an illustration. In Chapter 3, this methodology is applied to the integrated care setting of cerebral palsy in each of the three care regions, identifying experienced gaps in parent-professional and inter-professional communication from both the perspective of parents as well as involved professionals.

The second part of this thesis is focused on obtaining insight in the feasibility and usability of an eHealth application to improve communication across the integrated care setting of cerebral palsy in each of the three care regions. Based on the gaps and needs for improvement identified in the first phase of the study, we developed an asynchronous secured web-based system for parent-professional and inter-professional communication. In Chapter 4 we describe its design features, technical feasibility and clinical usability, as well as parents' and professionals' actual system use in a 6-month pilot in each of the three care regions. In Chapter 5 we focus on determinants of use and non-use of professionals, evaluating whether their use of the web-based system was associated with their a priori expectancies and background characteristics. In Chapter 6 we perform an in-depth evaluation of the system's contribution to parent-professional communication, as experienced by those parents who had used the system during the 6-month pilot. Finally, Chapter 7 presents a general discussion on how to progress towards improved communication in integrated care settings such as cerebral palsy.

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CHAPTER 2

EVALUATING QUALITY OF PATIENT CARE COMMUNICATION IN INTEGRATED CARE SETTINGS:

A MIXED METHOD APPROACH

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Abstract

Background. Owing to the involvement of multiple professionals from various institutions, integrated care settings are prone to suboptimal patient care communication. To assure continuity, communication gaps should be identified for targeted improvement initiatives. However, available assessment methods are often one-sided evaluations not appropriate for integrated care settings.

Objective. We developed an evaluation approach that takes into account the multiple communication links and evaluation perspectives inherent to these settings. In this study, we describe this approach, using the integrated care setting of cerebral palsy as illustration.

Methods/Results. The approach follows a three-step mixed design in which the results of each step are used to mark out the subsequent step's focus. The first step patient questionnaire aims to identify quality gaps experienced by patients, comparing their expectancies and experiences with respect to patient–professional and inter-professional communication. Resulting gaps form the input of in-depth interviews with a subset of patients to evaluate underlying factors of ineffective communication. Resulting factors form the input of the final step's focus group meetings with professionals to corroborate and complete the findings.

Conclusions. By combining methods, the presented approach aims to minimize limitations inherent to the application of single methods. The comprehensiveness of the approach enables its applicability in various integrated care settings. Its sequential design allows for in-depth evaluation of relevant quality gaps. Further research is needed to evaluate the approach's feasibility in practice. In our subsequent study, we present the results of the approach in the integrated care setting of children with cerebral palsy in three Dutch care regions.

Introduction

In literature, various terms and definitions are used in reference to integrated care. The essence though is similar: when separate agencies or individual professionals do not cover the complete range of patient care, they need to collaborate and coordinate their services in order to achieve continuity. Although the aims of integrated care are mostly similar (i.e. the provision of comprehensive, coordinated and continuous services [1]), broad differences exist in translating these aims in practice. In this study, we refer to 'integrated care settings' as settings in which a network of multiple professionals from various organizations is involved to meet each patient's care needs. Consequently, the level of integration may vary broadly, from merely 'linkage' (caregivers of one organization seek outside providers with special know-how and complementary care services while remaining within the context of existing, fragmented systems) to highly structured forms of coordination in which the full spectrum of care is managed by creating new organizational infrastructures [2].

Regardless of the level of integration, in order to achieve comprehensive, coordinated and continuous services, optimal patient care communication is indispensable. In this study, we approach patient care communication along two axes: between patients and providers and among providers. Whereas patient– provider communication is predominantly relational in nature, requiring 'productive interactions' between the patient/family and the health care team, inter-provider communication primarily involves effective and efficient information exchange across services and settings so that appropriate information reaches those who need it at the appropriate time. Given the involvement of multiple professionals, integrated care settings are prone to gaps in both axes of communication [3]. To assure continuity of care, it is imperative to identify these gaps in order to implement targeted improvement initiatives. However, available assessment methods are often one-sided evaluations not appropriate for integrated care settings, as we illustrate below. To identify communication gaps relevant to both patients and professionals, we developed an evaluation approach that takes into account the multiple communication links and evaluation perspectives inherent to integrated care settings. In this study, we describe this approach, using the complex integrated care setting of cerebral palsy as illustration (see Box 1).

Box 1. Cerebral palsy: a complex integrated care setting

Cerebral palsy (prevalence 1.5-2.5/1000 live births) is an umbrella term for impairments in posture- and/ or motor function as a result of peri-natal disturbances in the development of the brain. Dependent on the affected parts of the brain, the impaired posture/ motor function can be accompanied by mental retardation, psychosocial problems, epilepsy, visual, hearing or speech impairments etcetera. To meet the differential care needs of each patient, multiple professionals from various institutions are involved, from (specialized) hospitals to primary care centres, from day-care to (special) education centres. To assure continuity of care, coordination across these settings is essential, though in practice this can be easily affected by suboptimal patient care communication, both among providers as well as with patients and their family.

Shortcomings of available assessment methods

In order to find appropriate assessment methods for evaluating quality of communication in integrated care settings, we conducted a Pubmed search covering studies with abstracts published in English between 1 January 1990 and 31 January 2007. The following MeSH-terms were used: '(investigative techniques) and (communication barriers or inter-professional relations) and (primary health care or delivery of health care, integrated or chronic disease)'. The majority of the resulting 440 studies could be excluded after screening of titles. The abstracts of the remaining 76 studies were judged by two of the authors on the basis of the following inclusion criteria: (i) study aim evaluation of patient care communication and (ii) focus on communication across settings and (iii) description of used assessment methods.

In total, 26 studies [4–29] met the inclusion criteria. In table 1 an overview is given for their focus, aim, methods and evaluation perspective. Although each study evaluated communication across settings, we found none of them used assessment methods appropriate for application in integrated care settings. Among the most important shortcomings were:

- *Evaluation of only one communication link*, e.g. the communication between hospital specialists and general practitioners [7, 8, 10, 15, 16, 19, 24, 25, 27–29] or the communication between hospital specialists and primary care physicians [4, 6, 11, 12, 14, 18, 20, 22, 23, 26]. To evaluate patient care communication in integrated care settings, communication links across the whole network should be taken into account.

- *Focus on only one aspect of communication*, e.g. referral communication [4, 5, 10, 22, 26, 27] or discharge communication [6, 15, 16, 24, 25]. For a comprehensive evaluation, the broad spectrum of patient care communication should be taken into account, both inpatient and outpatient.
- *Inclusion of only one evaluation perspective*, e.g. the perspective of general practitioners [7, 8, 10, 13, 24, 25, 28, 29] or the perspective of primary care physi- cians [5, 18, 20, 22]. Although various studies included two evaluation perspectives [4, 11, 12, 14, 17, 19, 21, 23], for evaluation of communication in integrated care settings it is imperative to consider the perspective of patients and various involved professionals;
- *Limited scope of evaluation data*, e.g. either obtaining overall, quantitative data through surveys and/or text analysis [4–7, 10, 12, 15–18, 20–24, 26, 27, 29] or in-depth, qualitative data from interviews or focus group meetings [9, 13, 14, 19, 28]. For an optimal understanding of the research problem both overall quantitative as well as in-depth qualitative data are needed.

Table 1. Study characteristics of the included 26 studies

Study	Focus	Aim	Methods	Perspective
Stille et al. [4]	Communication between primary care pediatricians (PCP) and pediatric specialists	To determine rates, clinical impact and determinants of PCP-specialist communication in pediatric outpatient referrals	Questionnaire	PCPs Pediatric specialists
Greene et al. [5]	Communication between primary care physicians (PCP) and chiropractors (DC)	To contrast referral patterns among PCPs with referral patterns to DC and to identify predictors of PCP referral to DC	Questionnaire	PCPs
Helleso [6]	Discharge communication between hospital nurses (HN) and home care nurses	To analyze language in HNs' discharge notes and to identify differences between paper and electronic discharge notes	Medical record review	X
Verdoux et al. [7]	Communication between GPs and psychiatrists	To explore how GPs collaborate with psychiatrists in the care of patients with early psychosis	Questionnaire	GPs

(continued) Table 1. Study characteristics of the included 26 studies

Study	Focus	Aim	Methods	Perspective
Farquhar et al. [8]	Communication between GPs and hospital specialists	To describe GPs' views of communication issues across the primary/ secondary interface in relation to ovarian cancer patients	Interviews Medical record review	GPs
Bruce and Suserud [9]	Handover and triage communication between ambulance crew and emergency nurses	To explore experiences of emergency nurses receiving patients brought by ambulance crew	Interviews	Emergency nurses
Jiwa et al. [10]	Referral communication between GPs and gastroenterologists	To invite GPs to set standard for referral letters to specialists and to apply these standards to actual referral letters	Questionnaire Medical record review	GPs
Satzinger et al. [11]	Communication between hospital nurses and home care nurses	To evaluate admission and discharge communication after implementation of a Patient Accompanying Form	Questionnaire Interviews	Hospital nurses Home care nurses
Stille et al. [12]	Communication between pediatric generalists (PCP) and pediatric specialists	To identify target areas for improvement of communication in the outpatient care of children with chronic conditions	Questionnaire	PCPs Pediatric specialists

(continued) Table 1. Study characteristics of the included 26 studies

Study	Focus	Aim	Methods	Perspective
McNulty et al. [13]	Communication between GPs and public health laboratory services (PHLS)	To determine how GPs perceived current lines of communication with PHLS and how these can be improved	Focus Groups	GPs
Stille et al. [14]	Communication between pediatric generalists (PCP) and pediatric specialists	To describe barriers and facilitators to effective communication in the outpatient care of children with chronic conditions	Focus Groups	PCPs Pediatric specialists
Jansen and Grant [15]	Communication between GPs and emergency department	To evaluate quality of computer generated discharge communication after accident and emergency attendance	Medical record review	X
Foster et al. [16]	Communication between GPs and hospital specialists	To assess quantity of information in discharge communication and to assess the time for GPs to receive it	Medical record review	X

(continued) Table 1. Study characteristics of the included 26 studies

Study	Focus	Aim	Methods	Perspective
Fairchild et al. [17]	Communication between primary care physicians (PCPs) and home care clinicians (HCCs)	To assess communication and collaboration between PCPs and HCCs	Questionnaire	PCPs HCCs
Pantilat et al. [18]	Communication between primary care physicians (PCP) and hospitalists	to determine PCPs' preferences for and satisfaction with hospitalists	Questionnaire	PCPs
Van der Kam et al. [19]	Communication between GPs and pharmacists	to assess whether electronic communication provides better information than paper based information	Interviews	Patients GPs Pharmacists
Barnes et al. [20]	Communication between primary care physicians (PCP) with radiation oncologists (RO)	To assess satisfaction and information needs in the care for patients who receive radiotherapy To compare PCP information needs to content of RO letters	Questionnaire Medical record review	PCPs
Mainous et al. [21]	Communication between GPs and chiropractors	To describe the communication and coordination of care and to identify potential barriers to effectively sharing care	Questionnaire	GPs Chiropractors

(continued) Table 1. Study characteristics of the included 26 studies

Study	Focus	Aim	Methods	Perspective
Forrest et al. [22]	Referral communication between primary care pediatricians (PCP) and hospital specialists	To describe how primary care pediatricians coordinate specialty referrals and to assess their satisfaction	Questionnaire Medical record review	PCPs
Cox [23]	Communication between hospital nurses & primary care nurses	To evaluate quality of communication at patient admission till discharge & the constraints to its free flow	Questionnaire Medical record review	Hospital nurses Primary care nurses
Paterson and Allega [24]	Communication between GPs and hospital specialists	To evaluate quality of handwritten faxed hospital discharge summaries	Questionnaire	GPs
Bolton et al. [25]	Communication between GPs and hospital specialists	To assess quality of discharge communication	Questionnaire Focus groups Medical record review	GPs
Anderson and Helms [26]	Communication between hospitals and nursing homes (NH) resp. home health agencies (HHA)	To describe and compare quality of referral communication between hospitals-NH and hospitals–HHA	Medical record review	X

(continued) Table 1. Study characteristics of the included 26 studies

Study	Focus	Aim	Methods	Perspective
Montalto et al. [27]	Communication from GPs to emergency physicians	to evaluate the quality of referral communication with GPs and its impact on patient management	Questionnaire	Emergency physicians
Wood [28]	Communication between GPs and cancer specialists	to evaluate how GPs perceive their role in follow-up care and which communication barriers exist in fulfilling this role	Focus Groups	GPs
Branger et al. [29]	Communication between GPs, pharmacists and hospital specialists	To evaluate quality of electronic communication in comparison to paper based communication at patient admission till discharge	Questionnaire Message flow measurements	GPs

Towards an evaluation approach for integrated care settings

On the basis of these shortcomings, the evaluation of patient care communication in integrated care settings should incorporate:

- an operationalization of patient care communication attuned to integrated care settings;
- a focus on various communication links across settings;
- a quality evaluation from the perspectives of patients and professionals;
- an integration of quantitative and qualitative assessment methods.

Before we translate these criteria into a new evaluation approach, we will first place each of them in a frame.

Operationalization of communication attuned to integrated care settings

In this study, we approach patient care communication along two axes: between patients and providers and among providers. Whereas patient-provider communication is predominantly relational in nature, communication among providers primarily involves effective and efficient information exchange. Therefore, in our evaluation approach we address two aspects of patient care communication: (i) inter-professional information exchange with dimensions such as timeliness, accessibility and appropriate amount of exchanged information [30]. (ii) patient-professional relational interactions with dimensions such as shared decision-making, empathy, openness and respect [31].

Focus on various communication links across settings

Given the multiple professionals that are involved in integrated care settings, our approach should include multiple patient-provider and inter-provider links. However, evaluation of the vast number of possible inter-provider links would be time consuming and practically impossible. Therefore, we propose to focus on links with professionals who are highly central to the care setting, in communication network theory also referred to as ‘star’-members [32]. In integrated care settings, this ‘star’-member usually is a primary care provider (PCP) given their ‘distinctive role in integrating the care that patients receive from within and outside of the primary care setting’ [33]. Dependent of the care setting, the PCP can be a family doctor, internist, paediatrician or geriatrist, or any other professional who takes care of the entire range of a person’s basic health care needs over a prolonged period of time (see Box 2).

Box 2. Multiple communication links in cerebral palsy care

Dependent on the life phase of patients with cerebral palsy, various professionals can fulfil the coordinating role of primary care provider (PCP). In young children with cerebral palsy, the PCP usually is a paediatrician, paediatric neurologist, or rehabilitation physician/ physiatrist. As highly central professionals in the care network, their communication links cross the integrated care network as a whole. Therefore, evaluation of inter-provider communication in the care of children with Cerebral Palsy should focus on communication links to- and from the child's PCP.

Quality evaluation from the perspectives of patients and professionals

Particularly in integrated care settings in which multiple professionals, disciplines and institutions are involved, the perspective of each professional is limited to the specific role they play in the care network. Patients on the other hand, come in contact with various professionals, disciplines and institutions, and thus are capable of providing feedback on the complete range of care. Consequently, we will use the patient perspective as central source of feedback in our approach. In evaluation research of service quality from the client's perspective, the expectancies/ experiences approach is often used [34]. Taking this approach as starting point in our evaluation, the concept of quality is operationalized as the degree to which patients' experiences meet their expectancies. A 'quality gap' is apparent when a patient's experiences do not match his/her expectancies with respect to a certain aspect.

Integration of quantitative and qualitative assessment methods

In the social and human sciences mixed method approaches are gaining increasingly attention because of their possibilities to optimize the potential of both quantitative and qualitative approaches [35]. By seeking convergence across different methods (known as 'triangulation') biases inherent to any single method can be neutralized. Further, the mixed method approach allows for a 'sequential design' in which the results from one method can be used to develop or focus the subsequent method.

Translation into a three-step mixed method approach

Translation of the above criteria resulted in the three-step mixed method approach presented in table 2. As shown, the approach works as a 'funnel', in which the focus of each subsequent step is a derivative of specific outcomes of the previous step. As such, the approach aims to identify those aspects of communication most in need of improvement to both patients as well as involved professionals.

Table 2. Schematic representation of the three-step mixed method approach to evaluate quality of communication in integrated care settings

	relevant communication links in the integrated care setting
	↓
I.	PATIENT QUALITY QUESTIONNAIRE
	communication links with quality gaps
	↓
II.	IN-DEPTH INTERVIEWS WITH SUBSET OF PATIENTS
	underlying factors of quality gaps
	↓
III.	FOCUS GROUP MEETINGS WITH INVOLVED PROFESSIONALS
	additional/ related factors
	↓
	relevant aspects for improvement

Relevant communication links in the integrated care setting

As mentioned, evaluation of the vast number of communication links in an integrated care setting would be time-consuming and practically impossible. Therefore, we need to determine relevant patient-provider and inter-provider links that should be included in the first step's patient questionnaire. In less complex integrated care settings, such as stroke, each patient follows a relatively similar care pathway. In these care settings, it often will be clear which care providers are involved and, accordingly, which patient-provider and inter-provider links should be included. In complex care settings such as diabetes or cerebral palsy, however, heterogeneous care needs leads to a broad range of individual care pathways. As a result, multiple care providers are involved, during a large or short time period, for a majority or only a minority of patients. To yield aspects of improvement that are relevant for most patients, the three-step evaluation approach should focus on communication links that occur in the care of the majority of patients. An objective way to determine these links is to perform a medical record review on the PCP's in- and outgoing cross-organizational correspondence, scoring the frequency of communication links. The proportion of patient records in which a link occurs as well as the frequency of that link's occurrence within each patient record determines the relative strength of each communication link. The strongest communication links derived from this analysis can subsequently be included in the first step patient questionnaire.

Step I: Quality evaluation through patient questionnaire

The aim of this step is to identify communication links in which patients experience quality gaps. Various patient questionnaires are available that evaluate overall quality of care and address patient care communication in separate items or subscales. Examples of validated measures include the Primary Care Assessment Survey [36] and the Measure of Processes of Care [37]. However, the communication items in these measures only focus on patients' overall experiences with communication and do not discriminate between various patient–provider and inter-provider links in the care setting. For the purpose of this evaluation step this distinction is essential. We therefore composed a patient questionnaire that evaluates patients' experiences and expectancies regarding the various patient-provider and inter-provider links in their care settings. Those links in which most patients experience quality gaps are used as an input for Step II.

Step II: In-depth interviews with subset of patients

To identify the factors that underlie the quality gaps, in-depth interviews are held with the patient subset that reported these gaps. A methodology that can be used to illuminate experiences and opinions of a small minority of respondents is the critical incidence technique, originally developed by Flanagan but since then applied in numerous studies to obtain concrete instances of effective and ineffective behaviour in any context [38]. In our approach, we primarily focus on examples of ineffective communication as these directly yield relevant aspects for improvement. The interviewer refers to gaps reported by the patient in the questionnaire and subsequently asks the patient to provide examples of situations in which he/she experienced these gaps. Each example is elaborated upon by posing predefined questions (i.e. what actually happened, who was involved, what led up to the situation, what were the consequences etc.). The aim of the interviews is not to obtain an exhaustive report about the origin of each individual communication problem, but to exceed the level of unique individual situations in search of themes applying to various patients and various experiences of one patient. These themes form the input of the final step of the evaluation approach.

Step III: Focus group meetings with involved professionals

The aim of this final evaluation step is to corroborate and complete the findings from the perspective of professionals. Hereto, a focus group approach is chosen, given its frequent application in multi-method strategies to interpret findings from other sources and to compare, challenge or support, but ultimately extend personal

meanings and experiences [38]. Although there are no general standards to conduct focus groups, they often (i) use homogeneous strangers as participants; (ii) rely on high moderator involvement; (iii) have 6–10 participants per group; and (iv) have a total of 3–5 groups per project [39]. For the purpose of this step, the focus groups consist of professionals that represent disciplines involved in the suboptimal communication links that resulted from Step I. The aim of the discussion is two-fold: (i) corroboration: do the professionals recognize the themes that emerged from the patient narratives? and (ii) completion: which additional factors do professionals experience in relation to these themes? Integrating the findings of the focus group meetings with those of the preceding in-depth interviews concludes the three-step sequential design. Together they form relevant aspects for targeted improvement initiatives.

Discussion

In contrast to available methods, the presented approach in this study evaluates patient care communication across the integrated care setting as a whole. By taking into account various communication links, evaluation perspectives and -methods, it forms a comprehensive approach that can be applied to a broad range of integrated care settings. What we need to consider, though, is whether this comprehensiveness does not come at the expense of the approach's feasibility in practice. A sequential design may in general be more time-consuming than the alternative 'concurrent design' in which multiple forms of data are collected all at once. On the other hand, a sequential design offers the possibility to first identify a subpopulation of relevant cases for subsequent in-depth evaluation. Also, the approach can be applied as a whole or in separate parts, dependent on the complexity of the studied integrated care setting and the existing information on quality of communication that is available in advance. In some settings, problematic communication links may be already known, leaving in-depth patient interviews and/or focus groups with professionals to identify underlying factors.

Another issue is the approach's validity. One of the utilities of mixed methods research is the possibility of internal validation through triangulation of data, i.e. comparing and complementing data as a means to confirm, cross-validate, or corroborate findings within a single study. In the presented three-steps sequential design, this comparison and completion of data is only relevant for the last two steps, given their mutual aim to evaluate underlying factors of experienced quality gaps. Therefore, we consider the approach's validity in an alternative context, i.e. the context of our pre-defined criteria with respect to what do we evaluate (i.e. operationalization of

patient care communication in integrated care settings) and how do we evaluate it (i.e. rationale of a mixed method design). With respect to the first criterion (what do we evaluate), we chose an operationalization of patient care communication in terms of patient-provider relational interactions (with dimensions such as shared decision-making, empathy, openness and respect) and inter- provider information exchange (with dimensions such as timeliness, accessibility and appropriate amount of exchanged information). Indeed, patient-provider links encompass dimensions of information exchange as well (just as inter-provider links also encompass relational interactions); we based our focus on the context in which patient-provider and inter-provider links primarily occur. With respect to the second criterion (how do we evaluate), we chose a funnel approach in which the results of each step are used to mark out the subsequent step's focus. From an improvement point of view, a gap is more relevant, when more patients and professionals experience it. Therefore, in Step I communication links are included that occur in the care of the majority of the patient population. And in Step II the links in which the most patients experience quality gaps are further evaluated.

To evaluate patient–provider and inter-provider links, we chose the patient perspective as central source of feedback. For patient–provider links, this seems logical as patients can report their direct experiences. With respect to inter-provider links, however, patients can only report indirect impressions of only a part of the total communication that takes place among professionals. Nevertheless, these indirect and incomplete impressions do provide insight in the core of inter- provider communication, namely its ultimate effects on the patient. The alternative (evaluation of inter-provider links from the PCP perspective) would inevitably result in overall experiences not related to individual patients, as evaluation of PCP's experiences regarding each of the various inter-provider links per individual patient would be impossible. Correspondingly, the aim of the critical incidence interviews is not to obtain an exhaustive report about the origin of each individual communication problem- indeed this would require chart-reviews and interviews with involved professionals as patients obviously cannot be aware of all aspects that led to the communication problem. The aim of the interviews is to exceed the level of unique individual situations in search of general themes that apply to various patients.

Dependent on the complexity of the integrated care setting, the three-step mixed design approach is preceded by a network analysis to identify relevant links in the care setting. An objective method for this analysis is a medical record review on the PCP's in- and outgoing cross-organizational correspondence. We preferred an objective method to score the relative frequency of communication links, as

subjective methods to (e.g. interviews with stakeholders) are susceptible to recall-bias. Finally, more information is needed regarding the minimal number of patients and professionals needed at each step to get a good picture. In step I, the minimal number of patients is hard to specify, as this would require power-calculations for which an estimated effect size is needed. This is complicated as integrated care settings differ substantially from one another and patient populations can be highly heterogeneous (especially in care settings like cerebral palsy). In step II, the subset of patients that are approached for in-depth interviews is a result of step I and thus variable in each evaluation. In studies on critical incidences, though, it is often mentioned that a saturation effect (i.e. no new incidents) when far more than 20 interviews are analysed. With respect to step III, focus groups are characterized by a small number of participants, often consisting of 6 – 10 participants per group [39]. In this study, we introduced a framework for evaluating patient care communication in integrated care settings, using the integrated care setting of cerebral palsy as an illustration. In our subsequent study, we apply the three-step evaluation approach in this complex care setting, in order to gain insight in the added value and feasibility of the approach in practice.

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CHAPTER 3

EVALUATING PATIENT CARE COMMUNICATION IN INTEGRATED CARE SETTINGS:

APPLICATION OF A MIXED METHOD APPROACH IN CEREBRAL PALSY PROGRAMS

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Abstract

Objective. In this study, we evaluated patient care communication in the integrated care setting of children with cerebral palsy in three Dutch regions in order to identify relevant communication gaps experienced by both parents and involved professionals.

Design. A three-step mixed method approach was used starting with a questionnaire to identify communication links in which parents experienced gaps. In subsequent in-depth interviews with parents and focus group meetings with professionals underlying factors were evaluated.

Results. In total, 197 parents completed the questionnaire (response 67%); 6% scored negative on parent–professional communication, whereas 17% scored negative on inter-professional communication, especially between the rehabilitation physician and primary care physiotherapy (16%) and (special) education/day care (15%). In-depth interviews among a subset of 20 parents revealed various sources of dissatisfaction such as lack of cooperation and patient centeredness, inappropriate amount of information exchange and professional use of parents as messenger of information. Focus group meetings revealed that professionals recognized these gaps. They attributed them to capacity problems, lack of interdisciplinary guidelines and clear definition of roles, but also a certain hesitance for contact due to unfamiliarity with involved professionals in the care network.

Conclusions. Parents particularly identified gaps in inter-professional communication between (rehabilitation) hospitals and primary care settings. Involved professionals recognized these gaps and primarily attributed them to organizational factors. Improvement initiatives should focus on these factors as well as facilitation of low-threshold contact across the patient's care network.

Introduction

Many patients are not reaping the benefits of advances in clinical and behavioural interventions in chronic illness care [1]. The Institute of Medicine attributes this to the increased demands on medical care and the inability of the system to meet these demands because of poorly organized delivery systems and constraints in using modern information technology [1, 2]. In order to improve delivery of care, effective system changes are required. The Chronic Care Model [3] identifies essential elements for these system changes, which in combination foster 'productive interactions' between informed patients and proactive practice teams [4]. In chronic illness care, these interactions between patients and practice teams usually involve a complex network of multiple professionals from various organizations. The many interactions in these 'integrated care' settings can be easily disturbed by suboptimal communication, with information passing inconsistently among professionals (often via the patient) and none of them having 'comprehensive care knowledge' [5]. In addition, there may be different interpretations of responsibility. When no provider is identified as care coordinator, there is a risk that a professional may incorrectly assume that another is addressing a particular patient concern while, in fact, it remains unattended [6, 7]. To assure continuity of care, it is imperative to identify communication gaps in order to implement targeted improvement initiatives.

However, available assessment methods are often not appropriate for integrated care settings, as usually only one communication link (e.g. general practitioner - hospital specialist) or one evaluation perspective (e.g. the perspective of primary care professionals) is taken into account [8]. Moreover, most studies rely on either quantitative- or qualitative methods, obtaining either general/population based data, or in-depth qualitative data derived from small samples [8]. In view of these shortcomings, we developed a three-step mixed method approach for evaluation of patient care communication in integrated care settings, which takes into account the inherent communication links and evaluation perspectives [8]. In this study this approach is applied to the complex integrated care setting of children with cerebral palsy (Box 1), with the aim to identify relevant gaps in patient care communication from both the perspective of parents as well as involved professionals.

Box 1. Cerebral palsy care in the Netherlands

In the Netherlands, paediatric rehabilitation services are delivered in both inpatient- and outpatient settings. The 23 national rehabilitation centres with paediatric facilities and the rehabilitation departments of all medium-sized and larger hospitals offer treatment on an outpatient basis only [24]. For inpatient treatment children can be referred to one of nine specialized, regional rehabilitation centres. Each year 9000 children are treated on an outpatient basis and 300 children on an inpatient basis [25]. More than half of these children have been diagnosed with cerebral palsy [24], an umbrella term for a group of motor disorders caused by a non-progressive lesion of the immature brain [26]. Impairments in posture- and/or motor function can be accompanied by various forms of co-morbidity such as mental retardation, psychosocial problems, epilepsy, visual-, hearing- or speech impairments. The Dutch population prevalence of cerebral palsy was calculated as 1.51 per 1000 inhabitants, rising significantly over time: from 0.77 (1977–79) to 2.44 (1986–88), a trend which is in accordance with other studies [27]. Because the needs and problems of children with cerebral palsy can be complex, a variety of professionals from different organizations are involved in the provision of care. In the Netherlands, cerebral palsy patients aged 4–8 years usually are under supervision of a rehabilitation physician in a (specialized) regional or academic hospital, which plays a coordinating role in the integral medical care [27]. At the age of 4, the children are either referred to regular schools (whether or not assisted by ambulant services) or schools for special education/ specialized day care centres. Children in regular education can often do with outpatient visits combined with mono-disciplinary therapy [28]. Schools for special education usually have close cooperation with the local rehabilitation centre and staff, taking part in multidisciplinary team conferences for treatment planning and evaluation [25]. Specialized day care centres are usually supported by ambulant consultation of the rehabilitation physician.

Methods

Study population

In order to obtain data representative for the Dutch population of cerebral palsy patients aged 4–8 years, we included three care regions across the Netherlands covering both urban to rural settings (table 1). The selection of patients was carried out by a rehabilitation physician, based on files of patients with annual supervision. Selection criteria were (i) diagnosis of cerebral palsy (confirmed by neurologist), (ii) age between 4 and 8 years (from the age of 4 diagnosis is mostly clear and (special) education becomes an additional communication partner in the care network) and (iii) parents with sufficient Dutch language skills (as determined by the rehabilitation physician) to complete the questionnaire and interview. The parents of the selected patients were approached for participation in the study by a written letter from their rehabilitation physician.

Table 1. Selected care regions for the recruitment of the study population (RP= rehabilitation physician)

Region	General characteristics	Organization of cerebral palsy care (4-8 years)
A	+/- 4 million inhabitants 15 hospitals (of which 3 academic) 5 rehabilitation centres	Majority of cerebral palsy patients under RP-supervision of an academic hospital
B	+/- 2,2 million inhabitants 12 hospitals (of which 1 academic) 2 rehabilitation centres	Majority of cerebral palsy patients under RP-supervision of a merged academic hospital/ rehabilitation centre
C	+/- 600.000 inhabitants 4 regional hospitals 1 rehabilitation centre	Majority of cerebral palsy patients under RP-supervision of a merged rehabilitation/ special education centre

Study design

For a detailed description of the methodology the reader is referred to our previous study [8]. Here we describe the subsequent steps that were followed in this study.

Identification of relevant communication links

To identify areas of improvement that are relevant to the setting as a whole, we focused on communication links that occur in the care of the majority of cerebral palsy patients. These were identified through a retrospective medical record review on the rehabilitation physician's incoming and outgoing cross- organizational correspondence [8]. We approached a rehabilitation physician in each region and randomly selected 63 medical records (21/region) of patients aged 9–12 years. Each record was reviewed retrospectively with respect to in- and outgoing letters during the age period 4–8 years, in which at least one of the listed senders/receivers was from another organization. Of these letters, all listed sender(s) and receiver(s) were imported in a database, thus forming an overview of communication links and their frequency of occurrence.

Step I. Parent questionnaire

Relevant links were subsequently included in a parent questionnaire, developed on the basis of validated frameworks [9, 10]. The questionnaire consisted of two parts: the first containing 10 items on the importance of various communication aspects in general, the second containing six sections, each representing a different

communication link and consisting of 15 items to get insight in the parents' experiences regarding this link over the past 12 months, using 5-point Likert- scales ('no, never' till 'yes, always'). Negative scores on communication links (i.e. 'no, never'/'no, usually not') were further explored in the subsequent step's in-depth interviews. The questionnaire was sent with an accompanying letter of the rehabilitation physician, requesting to return within 2 weeks filled in or blank if not willing to participate. After 2 weeks parents were reminded by letter and after 4 weeks by telephone.

Step II. In-depth interviews with subset of parents

The subset of parents who experienced gaps was, after informed consent, approached for in-depth telephone interviews to identify underlying factors of ineffective communication using an adaptation of the 'critical incidence' approach [11]. Parents were asked to give examples of situations in the past 12 months in which they experienced gaps in communication. Each of these 'critical incidents' was subsequently explored in detail through structured questions. All interviews were audio-taped and transcribed afterwards. The examples of ineffective communication were subsequently scored by two of the authors [JG and JvGP], identifying underlying factors by means of a framework covering aspects essential for integrated care, based on the key elements of the Chronic Care Model [3] and quality of care aspects formulated by the Institute of Medicine [2], all listed in table 2.

Step III. Focus group meetings with involved professionals

Issues emerging from the interviews were used as input for the focus group meetings (one meeting per care region with 10– 12 professionals) covering the various professional disciplines involved in the problematic communication links identified in Step I and II. The aim of the meeting was two-fold: (i) corroboration of findings (do the professionals recognize the problems experienced by parents?) and (ii) completion of findings (which additional issues are experienced?). During the meeting, the professionals were confronted with the results of the first two steps and asked to respond, and subsequently to discuss additional communication challenges they experience in relation to these problems. The discussion was moderated by an independent chair and conclusions were reached on the basis of consensus. Integrating the results of the focus group meetings with those of the in-depth interviews concludes the three-step sequential design, yielding relevant aspects for targeted improvement initiatives.

Table 2. Quality dimensions used for in-depth interviews (as derived from quality frameworks [2,3,10])

Quality dimensions			Operationalization
Organization of care		Capacity	Availability and accessibility of required people/ resources
		Infrastructure	Organizational structure of care/ care pathways
		Cooperation	(Readiness) to cooperate with involved professionals/ parents
		Competence	Know-how/ skills/ experience of involved professionals
		Joint vision/ policy	Interdisciplinary guidelines/ vision guiding patient treatment
		Roles/ tasks/ responsibilities	Transparency of- and agreement with individual- and mutual roles/ tasks/ responsibilities
		Patient centeredness	Providing care that is respectful of- and responsive to patient preferences, needs and values
		Coordination	Organizational activities aimed at achieving the appropriate care on the appropriate place and time
Information (-exchange)	Content	Understandability	Received information is clear and comprehensible for the receiver
		Relevancy	Received information is relevant for the receiver
		Consistency	Received information is not contradictory to earlier received information
		Completeness	Received information is complete
		Accuracy	Received information is correct/ free of error
	Exchange	Indirect links	Path between two actors is mediated by one or more others
		Availability	Required information is present in concerning files
		Accessibility	Required information is accessible for those who need it
		Timeliness	Required information is received in-time by those who need it
		Appropriate amount	Required information is exchanged in an appropriate amount

Results

Relevant communication links

In total, 63 records (21 records/region) were reviewed. Within these records 962 letters were analyzed (mean 16 letters per record, range 1–39), resulting in 1733 contacts to- and from the rehabilitation physician.

Table 3 presents the various communication links in these contacts. The table shows multiple senders and receivers, well illustrating the links in an integrated care setting, in which multiple professionals from various organizations are involved. In (rehabilitation) hospitals, the paediatrician, neurologist, (orthopaedic) surgeon, radiologist (as sender of information), physiotherapist and (colleague) rehabilitation physician were identified as the rehabilitation physician's most frequent communication partners. In primary care, the rehabilitation physician's most frequent communication partners were the general practitioner (only as receiver) and the primary care physiotherapist. For (special) education and day-care centres, these were the teacher/supervisor (primarily as sender) and physiotherapist. Other frequent partners were health insurers (as receiver of information), manufacturers of rehabilitation aids (as sender) and parents of cerebral palsy patients (primarily as receiver of information).

Table 3. Communication links to- and from the rehabilitation physician (RP, total 1733 contacts)

Communication links	To RP (n=591) %	From RP (n=1142) %
Teacher/ supervisor	15	7
Surgeon	14	12
Rehabilitation physician	12	8
Paediatrician	11	13
Physiotherapist	11	8
Radiologist	10	0
Manufacturer rehabilitation aids	6	0
Neurologist	6	8
General practitioner	1	22
Health insurance	1	8
Other professionals* (each <2%)	12	5
CP patients' parents	2	9
total	100	100

* other (para-)medical specialists and community health service workers

Step I. Parent questionnaire

All links in table 3 were included in the subsequent questionnaire, which was sent to the parent-pairs of 296 patients (in the remainder indicated as 'parents'). Of the 197 parents that completed the questionnaire (response rate 67%), 88% were female. The main reasons for non-response were lack of time or personal circumstances. As can be seen in table 4, overall scores were quite positive, with the majority of parents indicating that the parent–professional and inter-professional communication was good during the past 12 months. In comparison with parent–professional communication, inter-professional communication had more negative scores, particularly the inter-professional communication with the general practitioner, primary care physiotherapist and professionals of (special) education/day-care centres. Of the parents that scored negatively on inter-professional communication with the general practitioner, the majority indicated that the general practitioner did not play a relevant role in the communication regarding their child's care, given the highly specific nature of their child's problems. Combined with the findings of the medical record review (i.e. the general practitioner as receiver of information, instead of sender), the communication with the general practitioner was not further explored in subsequent in-depth interviews.

Table 4. Parents' experiences with parent-professional and inter-professional communication in their child's care (RP= rehabilitation physician)

	'usually/ always' %	*'occasionally not'* %	*'usually not/ never'* %	Nvalid
'The communication between (involved professionals of) the {.....} and us as parents was good during the past 12 months'				
Hospital	84	15	1	180
General practitioner	87	11	2	97
Rehabilitation centre	74	21	5	117
Primary care physiotherapist	93	7	0	105
Health Insurance	75	18	7	184
(Special) education/ day care centre	86	14	0	188
'To my impression, the communication among our child's RP and (involved professionals of) the {.....} was good during the past 12 months'				
Hospital	78	19	4	171
General practitioner	66	18	16	85
Rehabilitation centre	78	18	3	116
Primary care physiotherapist	64	20	16	103
Health Insurance	84	7	10	146
(Special) education/ day care centre	72	13	15	137

Step II. In-depth interviews with subset of parents

Those parents with negative scores on the inter-professional communication with the primary care physiotherapist (n=16 parents) and professionals of (special) education/ day care centre (n=21 parents) were included for in-depth interviews. As nine parents indicated problems in both links, in total 28 parents were approached. Of these, two refrained from participation due to personal circumstances and six indicated that although the communication among the involved professionals was not good during the preceding 12 months, they were used to act as intermediary and were satisfied with this solution. In the in-depth interviews among the remaining 20 parents, 11 parents reported gaps in the communication between the rehabilitation physician and primary care physiotherapist, 15 between the rehabilitation physician and professionals of (special) education/ day care centre and 8 between these professionals and themselves as parents (Box 2).

Box 2. Citations of gaps experienced by parents

- *"After visiting my daughter's new school, I had the impression something was wrong with her chair. Upon asking the occupational therapist indeed the chair and other things had to be adjusted. [...] I am constantly on top of things, but what about children with less assertive parents?"*
- *"When we finally got a walking aid for our son after a long tedious administrative process, the school therapists could not reserve sufficient time to train our son with it. Despite our frequent instigation on more time investment, they did not spend more time in training, responding that it was a task of the therapists in the rehabilitation centre, which in turn said they had no time either"*
- *"Professionals should have direct contact with each other […] Now it all goes through us parents and we are not experts"*
- *"After Botox treatment, the rehabilitation physician advised physiotherapy 5 times a week. At school however, this frequency turned out to be unfeasible and instead a lower frequency was deployed. The rehabilitation physician however did not get informed and only learned of it when confronted with the results"*
- *"Sometimes it feels like the garden first has to be over- grown with weeds before they are removed"*
- *"In our experience it depends strongly on the physiotherapist that is in place, which changes per school year. Our previous physiotherapist was very active and initiated personal contact with the rehabilitation physician. Although this was not the usual procedure, the lines were considerably shortened"*
- *"If you don't check up on it as a parent, the information will not arrive in time, or worse, does not arrive at all"*
- *"Our rehabilitation physician and physiotherapist dis- agreed regarding the use of braces; the first was in the opinion that it was 'in no hurry' and that the muscles 'were still flexible enough', the physiotherapist however warned not to wait with the measurement of braces until the muscles were fixed and stuck. As a parent you sit in between and that is very difficult: who should you believe?"*
- *"We constantly have to tell the same story over and over again. As if you come for administration, instead of advice on your child's care"*

Table 5 gives an overview of the factors identified. Overall, 60% of the experienced gaps was related to organization of care and 40% to information exchange. The main underlying factors were lack of cooperation and patient centeredness (parents constantly had to check up on agreements and progress or were confronted with professionals sticking to their view how things need to be done, not willing to take into account another professional's view) and inadequate information exchange between professionals, resulting in the necessity for parents to act as messenger between professionals.

The underlying factors differ between the communication links; between the rehabilitation physician and professionals of (special) education/day care centre, lack of cooperation was particularly evident (20% of the problems), whereas between the rehabilitation physician and physiotherapist, capacity, infrastructure and consistency of information were problematic issues.

Table 5. Underlying factors of experienced gaps, as derived from in-depth parent interviews (RP = rehabilitation physician)

		Overall N= 171 problems %	RP-primary care physiotherapy N= 68 problems %	RP-education / day care centre N= 69 problems %	Parent-professional communication N= 34 problems %
Organization of care	Cooperation	15	12	20	12
	Patient-centeredness	13	7	7	35
	Competence	8	7	6	12
	Joint vision/ policy	6	4	7	6
	Capacity	6	9	4	3
	Infrastructure	5	9	4	0
	Coordination	4	0	6	6
	Roles/ tasks/ responsibilities	4	3	6	0
	total	60	51	61	74
Information (exchange)	Appropriate amount	15	19	17	3
	Indirect links	12	15	13	3
	Completeness	5	3	3	12
	Timeliness	4	4	3	3
	Consistency	3	6	1	0
	Other factors* (each ≤ 1%)	2	1	1	6
	total	40	49	39	26

* availability, accessibility, understandability and accuracy of information

Step III. Focus group meetings with involved professionals

The focus group meetings with involved professionals showed that professionals recognized parents' experiences with lack of cooperation, especially in the communication between hospital and (special) education/ day care centre. They primarily related this problem to the lack of inter-disciplinary guidelines and clear definition of roles, tasks and responsibilities. Diverging views among professionals might account for the experienced lack of consistency in information exchange between the rehabilitation physician and primary care physiotherapist. However, this is partly inevitable as the frequency of patient contacts varies considerably among professionals; for example, the rehabilitation physician generally checks on the patient once or twice a year, the primary care physiotherapist once a week.

The lack of inter-professional information exchange was particularly recognized in the communication between hospitals and the periphery. Apart from capacity problems it was also attributed to the fact that it is often unclear which professionals are involved in the network around a child. In addition, professionals mentioned a certain hesitance to contact professionals with a different background or -focus; rehabilitation physicians said they practically never contacted professionals from regular education, only ambulant supervisors from special education that support regular education. Related to this, professionals confess they are regularly inclined to ask parents to act as messenger of information ('then you know for sure that it reaches the right person in time'). They recognized, however, that some parents experience this messenger role as a burden, especially when entrusted with communicating oral messages, which due to medical/technical terms are easily misunderstood.

Discussion

In this study, a three-step mixed method approach was applied to evaluate communication gaps in the integrated care setting of children with cerebral palsy. From the parent perspective, most frequently experienced problems were lack of cooperation and patient centeredness, inadequate information exchange among professionals and the necessity to act as messenger of information between professionals. From the professionals' perspective, these problems were recognized and related to lack of interdisciplinary guidelines and clear definition of roles, capacity problems, lack of network transparency and a certain hesitance for contact with professionals with a different professional background.

These results are relatively consistent with findings in literature. Stille et al. [12, 13] found various gaps in the communication between paediatric specialists and

primary care paediatricians, such as frequent failure or inability to contact each other and difficulties in keeping all providers informed. In a recent study [14], Stille et al. compared the views of parents, primary care paediatricians and specialists regarding the perceived responsibilities of parents acting as information intermediaries. One-third of the parents reporting to be the primary communicators between their children's' physicians, felt uncomfortable in that role. On the other hand, as long as professionals do not depend on it, the messenger role can be positive, as parents can put the message into the context of the child, thus providing 'whole care knowledge' which adds to the provision of 'whole-person care' [5].

Comparing our findings with the Chronic Care Model [3] the experienced lack of patient centeredness relates to the concept of 'self management support', stressing the importance of a collaborative approach in which providers and patients work together to define problems, set priorities, establish goals, create treatment plans and solve problems along the way [4]. The experienced lack of inter-professional cooperation and -information exchange is linked with the model's health system level, emphasizing the need of agreements that facilitate data-sharing as patients navigate across settings and providers. These should cover the definition of roles and the distribution of tasks among team members, and the use of evidence-based guidelines for decision support in daily clinical practice [4].

By taking into account various communication links, evaluation perspectives and methods, the mixed-method approach presented in this study forms a comprehensive approach that can be applied to a broad range of settings in which multiple professionals from various organizations are involved. The question is whether this comprehensiveness does not come at the expense of feasibility in practice. A sequential design may be more time-consuming than the 'concurrent design' in which multiple forms of data are collected all at once [15]. On the other hand, a sequential design offers the possibility to first identify a subpopulation of relevant cases for sub- sequent in-depth evaluation. Moreover, it can also be applied in separate parts, dependent on the complexity of the studied setting and the existing information on quality of communication that is available. In some settings, problematic communication links may be already known, leaving in-depth patient interviews and/or focus groups with professionals to identify underlying factors.

In the literature various challenges are described regarding the integration of findings from various evaluation perspectives and methods [16]. Erzberger and Kelle [16] outlined two models of integration: the 'triangulation model' (in which the purpose is mutual validation) and the 'complementarity model' (in which the purpose is more complete understanding). In the present study, the purpose of each subsequent

step was both corroboration as well as completion of findings. One should be aware however that convergent findings do not necessarily prove validity, as the findings can be biased for the same reason in the same direction [16].

Several observations can me made concerning the methodology used in this study. As a form of network analysis a medical record review was performed on the rehabilitation physician's in- and outgoing cross-organizational correspondence. Although it offered insight in the various links and differences across the regions, its focus was on only one node of a complex web of interconnections and it only included written correspondence. In addition informal communication might have been valuable, which could have been identified by methods like selected stakeholder interviews.

The medical record review revealed a one-directional communication between the rehabilitation physician and the general practitioner. The reason for this scarce communication can be 2-fold: either it is not necessary, or it is not carried out. The majority of parents reported that, given the highly specific nature of the problems, the general practitioner did not play a relevant role in their child's care communication. The communication with the general practitioner was thus not further explored but we cannot completely rule out the possibility that an important gap of communication was left out.

A new questionnaire was developed in the present study to evaluate parents' expectations and experiences regarding parent-provider and inter-provider communication as the various existing validated measures [17-20] do not primarily focus on patient care communication nor discriminate between the various patient-provider and inter-provider interactions. Although no data are available on reliability or validity, the questionnaire was constructed using validated measures [9, 10] and frameworks.

To identify gaps, both parent – professional and inter- professional links were analysed. For parent-professional links, evaluation from the parents' perspective seems logical, whereas for inter-professional communication parents can only report on its ultimate effects on the child, albeit through indirect and probably incomplete impressions, which might have biased the results in a negative sense for these links. Besides, parents with insufficient Dutch language skills were excluded. This might also have biased the findings in terms of under-rating parent- provider communication problems. On the other hand, the questionnaire responses may have over-rated the level of parent satisfaction, as satisfaction scores on structured questionnaires may be substantially an artefact of the method of data collection [21, 22], indicating higher and more positive assessments than revealed through in-depth qualitative interviews.

Overall, the gaps identified in this study argue for improvements focused on cooperation and patient centeredness, inter-professional information exchange and organizational factors such as interdisciplinary guidelines and clear definition of roles and network transparency. An initiative that might be promising in this respect and that emerged from group discussions with professionals and parents is a secured platform on the internet, where parents can contact the network of involved professionals in their child's care and involved professionals can consult each other. In the literature, this idea of online communication to enhance access and transparency of care is gaining ground [23].

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CHAPTER 4

A WEB-BASED COMMUNICATION SYSTEM FOR INTEGRATED CARE IN CEREBRAL PALSY:

DESIGN FEATURES, TECHNICAL FEASIBILITY AND USABILITY

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Abstract

Background. We developed a secure, web-based system for parent-professional and inter-professional communication. The aim was to improve communication in the care of children with cerebral palsy.

Methods. We conducted a six-month trial of the system in three Dutch health-care regions. The participants were the parents of 30 cerebral palsy patients and 120 professional staff involved in their care. Information about system usage was extracted from the system's database. The experience of the parents and professionals was evaluated by a questionnaire after six months.

Results. The system proved to be technically robust and reliable. A total of 21 parents (70%) and 66 professionals (55%) used the system. The parents submitted 111 questions and 59 responses, with a mean of 5 questions (range 1–17) and 3 responses (range 1–9) per parent. The professionals submitted 79 questions and 237 responses, with a mean of 2 questions (range 1–8) and 4 responses (range 1–23) per professional. Most parents (95%) and some professionals (30%) reported value in using the system, which ranged from efficiency and accessibility to flexibility and transparency.

Conclusions. The web-based communication system was technically feasible and produced improved parent-professional and inter-professional communication. It may be especially valuable if frequent interventions or consultations about a child's care are required, involving complex care networks of different professionals and organisations.

Introduction

Chronic care often requires a complex care network of multiple professionals from different organizations. In such settings the patient-provider and provider-provider interactions can be disturbed easily by poor communication, with information passing inconsistently among providers and none of them having 'comprehensive care knowledge' [1]. In the US national survey of children with special health care needs, communication between doctors and other providers was found to be a particular area of weakness, with only 37% of parents reporting it as very good to excellent [2]. Failure of professionals caring for the same child to communicate with one another often leaves the parents as information intermediaries [3]. This corresponds with our findings in the care of children with cerebral palsy in the Netherlands (Box 1), in which we identified various gaps in patient care communication, such as the lack of cooperation, not being sufficiently patient-centred, poor inter-professional information exchange leading to parents acting as messengers of information, and hesitation in making contact due to unfamiliarity with the professionals in the care network [4].

Various recommendations have been made to improve patient care communication. The US Institute of Medicine has stressed the importance of effective use of information technologies and coordination of care across patient- conditions, services and sites [5]. Web-based communication may enhance access and efficiency, but has been slow to diffuse into clinical practice [6-7]. One of the factors associated with this slow diffusion is the necessity to take into account the needs of users in the development process [8]. We have applied a patient-centred approach, in which we translated the user needs identified in our previous study [4] into a secure, web-based system for parent-professional and inter-professional communication in the care of children with cerebral palsy. The aims were: (i) to make communication more patient-centred; (ii) to facilitate inter-professional contact and thereby reduce the need for parents to act as messengers of information; and (iii) to increase network transparency and provide more insight about who is involved in patient care and communication.

Box 1. Cerebral palsy care in the Netherlands

In the Netherlands, paediatric rehabilitation services are delivered in both inpatient and outpatient settings. The 23 national rehabilitation centres with paediatric facilities and the rehabilitation departments of all medium-sized and larger hospitals offer treatment on an outpatient basis only. For inpatient treatment, children can be referred to one of nine specialised, regional rehabilitation centres. Each year almost 7000 children are treated on an outpatient basis and about 400 on an inpatient basis [17]. More than half of these children have been diagnosed with cerebral palsy [18], an umbrella term for a group of motor disorders caused by a non-progressive lesion of the immature brain [19]. Impairments in posture and/or motor function can be accompanied by various forms of co-morbidity such as mental retardation, psychosocial problems, epilepsy, visual-, hearing- or speech impairments. The prevalence of cerebral palsy in the Dutch population is 1.51 per 1000 inhabitants, and is rising significantly: from 0.77 (1977–1979) to 2.44 (1986–1988), a trend that is in accordance with other studies [20].

Because the needs and problems of children with cerebral palsy can be complex, a variety of professionals from different organizations is involved in the provision of care. In the Netherlands, cerebral palsy patients aged 4–8 years are usually under the supervision of a rehabilitation physician in a (specialized) regional or academic hospital, which plays a coordinating role in the integral medical care [20]. At the age of 4 years, the children are either referred to ordinary schools (whether or not assisted by ambulant services) or schools for special education or specialized day-care centres. Children in ordinary education can often manage with outpatient visits combined with mono-disciplinary therapy [21]. Schools for special education usually have close cooperation with the local rehabilitation centre and staff, taking part in multidisciplinary team conferences for treatment planning and evaluation [18]. Specialized day care centres are usually supported by consultations with the rehabilitation physician.

Methods

Functional specifications were formulated for each of the three system aims, based on the needs of parents and professionals in three Dutch care regions [4]. These specifications were subsequently translated into technical requirements, which formed the basis of the system prototype. The prototype was developed iteratively, integrating the feedback from parents and professionals. Its technical feasibility (i.e. robustness and stability) was assessed through parents' and professionals' feedback in helpdesk correspondence and information meetings (one in each health-care region, after about three months of system use).

Information about system usage was extracted from the system's database. The early experience of parents and professionals was assessed through a questionnaire after a six-month trial of use, focussing on the value experienced (using a Likert scale, ranging from 1= 'no, not at all' to 5= 'yes, definitely'). Any shortcomings or suggestions for improvement were requested in a free text area.

In addition, we examined whether system use was related to the complexity of the child's care by comparing characteristics such as the number of institutions and professionals involved for users and non-users.

Participants

In order to obtain data representative of Dutch cerebral palsy patients aged 4–8 years, we included three health-care regions in the Netherlands covering both urban to rural settings. A rehabilitation physician selected patients who were under annual supervision. The selection criteria were a diagnosis of cerebral palsy and age 4–8 years. Participating parents needed to have sufficient Dutch language skills to be able to use the communication system and complete questionnaires. Finally, at least three professionals (i.e. the child's rehabilitation physician, a physiotherapist and a school/day care professional) needed to participate in the study in order to have a sufficient network for communication.

In total 30 parent-pairs were included in the study, together with 120 professionals. Ethics approval for the study was not required, although both parents and professionals provided informed consent. They completed a baseline questionnaire, after which they received log-in details for system access. Of the cerebral palsy patients (mean age 5.7 years, range 4–8), 13 attended ordinary education (with or without ambulant supervision) and 17 visited special education/day care centres. The mean number of professionals per child was 8 (range 3–14), of which the mean proportion participating in the study was 81% (range 50–100).

Design features

The overall system aims, and corresponding functional specifications and technical requirements are summarised in table 1. The system was developed on the basis of these design features, and comprised an open access part (a generally accessible website with project related information) and a secured access part, with password authentication, SSL encryption and retyping an alphanumerical code. After log-in, users could see the menu for administrators, parents or professionals.

Results

The system proved to be technically robust and reliable. In the initial testing period, during the first month, some minor technical problems were solved. In the remainder of the six-month trial there were no further technical problems. The helpdesk was only consulted for support (e.g. user instructions, resending log-in data) and feedback (sharing experiences and suggestions for improvement).

Table 1. System aims and corresponding functional specifications and technical requirements

Aims	Functional specifications	Technical requirements
Patient centeredness	• enable parents to consult the professionals involved in their child's care when necessary • enable professionals to consult parents when necessary • enable consistency of information in the provided response to parents	• overview of the child's care network in which parents can tick mark one or more professionals for consultation • overview of the child's care network in which professionals can tick mark the child's parents for consultation • parents' assignment of one feedback-responsible professional for the consultation question
Inter-professional contact	• enable professionals to consult other professionals involved in the child's care; • notify professionals as soon as they are consulted/ responded to • enable inter-professional conference prior to feedback to parents	• overview of the child's care network in which professionals can tick mark one or more professionals for consultation • automatic email-alerts with hyperlink to the submitted question/ response • submitted reactions from professionals only visible among involved professionals
Network transparency	• stimulate network contact over one-to-one interactions • enable network-wide insight in conducted consultations • provide an up to date overview which professionals are involved in the child's care network	• default cc of submitted question to other professionals in the child's network • up to date overview of the child's care network, specifying names specialities and affiliations of involved professionals
General aims	• provide open access information about system aims and procedures • warrant safe information exchange • enable independent system administration and assistance to system users when needed • up to date information regarding personal details	• generally accessible website with project related information • secured log-in with ssl-encryption and retyping an alphanumerical code • administrator menu for registration of system users and helpdesk function • personal menu in which parents and professionals can edit their personal details

System use

Of the participating parents and professionals, 21 parents (70%) and 66 professionals (55%) actively used the system by submitting one or more questions and/ or responses. Of the parents, the majority (n = 18) submitted both questions and responses, while 3 only submitted questions. Of the professionals, 34 only submitted responses, 26 submitted both questions and responses, and 6 only submitted questions. The parents' system use exceeded that of the professionals: 43% of the parents vs. 14% of the professionals used the system relatively often (in total ≥10 submitted questions or responses) and 40% of the professionals vs. 19% of the parents rarely used the system (in total ≤2 submitted questions or responses).

In total, parents submitted 111 questions and 59 responses, with a mean of 5 questions (range 1–17) and 3 responses (range 1–9) per parent. Of the 111 submitted questions, the rehabilitation physician was most frequently marked as responsible for feedback (in 41% of the 111 submitted questions), next to the physiotherapist, occupational therapist and teacher/ supervisor (marked in, respectively, 20%, 14% and 10% of the 111 submitted questions).

In total, professionals submitted 79 questions and 237 responses, with a mean of 2 questions (range 1–8) and 4 responses (range 1–23) per professional. The majority of questions were submitted by the physiotherapist (57%) and the majority of responses by the rehabilitation physician (35%) (see table 2). Of the total number of submitted questions (n=190) the purpose was primarily consultation or advice, followed by information sharing, monitoring and administrative purposes.

Factors associated with system use

We compared the number of professionals and institutions between parents who used the system (21 parents) and parents who had not used it (9 parents). The mean number of involved professionals in the use group was 8.3 (range 5-13) compared to 5.7 (range 3-10) in the non-use group, a significant difference (p= 0.006). The mean number of involved institutions was higher in the use group (mean 4.1 range 2-7) compared to the non-use group (mean 3.7 range 2-5), although this was not a significant difference.

Table 2. Summary of submitted questions (n=79) and responses (n=237)

	Questions		Responses	
	n	%	n	%
Physiotherapist	45	57	63	27
Teacher/ supervisor	8	10	20	8
Rehabilitation physician	6	8	84	35
Occupational therapist	5	6	28	12
Pedagogue	4	5	5	2
Manufacturer of rehabilitation aids	3	4	7	3
Paediatrician	1	1	7	3
Neurologist	0	0	4	2
Specialist mental retardation	1	1	2	1
Speech therapist	1	1	5	2
Social worker	1	1	5	2
Nurse	1	1	0	0
Creative therapist	1	1	4	2
Orthoptist	2	3	3	1
Total	79	100	237	100

User experience

Of the 30 participating parents, 26 completed the questionnaire after the six-month trial period (response 87%). Of these parents, 6 indicated that they had not used the system, either due to personal circumstances (indicated by 1 parent), preference for other modes of contact (3 parents), lack of need or not having questions (2 parents) or computer problems (1 parent). Of the 20 parents who had used the system, the majority had used it regularly (40%) or occasionally (50%), and 10% had used it rarely. All but one (95%) indicated that they had found it valuable, ranging from accessibility (questions could be asked at the moment they arose) to efficiency (the whole network could be reached at once, avoiding fruitless telephone calls) and transparency (it was possible to obtain an overview of questions and answers). In contrast, one parent indicated that there was no need for web-based contact, because their child was treated in a day-care centre with very short communication links.

Of the 120 participating professionals, 105 completed the questionnaire (response 88%). Of these professionals, 46 indicated that they had not used the system, either because they had not received any questions (37 professionals), preferred other modes of contact (12 professionals), had no time (2 professionals), did not know how to use the system (2 professionals) or had problems with their computer (1 professional). Of the 59 professionals who had used the system, the majority had used it occasionally (44%) or rarely (42%), while 8% had used the system regularly. Of the 59 professionals, 32% had found the system valuable in their communication with parents. With respect to the inter- professional communication, 29% of the professionals had found it valuable. Like parents, the value related to accessibility (lower threshold for consultation), efficiency (faster contact) and transparency (being kept up-to-date between visits, and obtaining insight about other professionals' advice). In addition, some professionals also mentioned that by using the system they had contact with disciplines that previously were not actively involved in decision-making and that this yielded important information.

The shortcomings experienced by parents and professionals were related to:

- Ease of use. This could be improved by simplifying the log-in procedure, expanding consultation options (e.g. attaching video files) and providing insight into the consultation process (e.g. providing reminders when questions are not answered);
- Integration of the system in daily practice. The system should be linked with existing patient documentation to avoid fragmented information. In addition, some professionals expressed the wish to consult external specialists for second opinions regarding complex matters, a feature not supported by the system which only enabled consultation within the child's care network;
- Target population. The system might be more valuable in younger age categories (early intervention period 0–4 years), given the frequent requirement for consultations to make a diagnosis, combined with the involvement of a scattered and changing network of professionals from different organizations. In addition, some parents proposed linking the system to an online support group.

Discussion

In order to develop a web-based communication system for the integrated care of cerebral palsy, we applied a patient-centred approach, translating the user needs that were identified in our previous study [4] into functional specifications and technical requirements. This approach allowed us to develop a web-based system geared to user needs and it represented a cost-effective design process [9].

However, the differences in system use between parents and professionals emphasize the importance of involving the users in an iterative development, adoption and implementation process, applying continuous feedback [10,11].

The system was evaluated regarding its technical feasibility and usability, which is analogous to a staged approach for telemedicine evaluation [12]. During the trial, approximately two-thirds of the parents and half of the professionals used the system by submitting questions or responses. The proportion of non-users may seem disappointing but might be related to the inclusion criteria, because the majority of non-users indicated that they already had short parent-professional or inter-professional communication links (e.g. face-to-face, by telephone or by email) or the child's situation was relatively stable during the six-month trial, so that little consultation was needed. In line with this, we found that the complexity of the child-care networks was associated with the parents' use of the system: the number of professionals involved was significantly higher for parents who used the system. Based on this we hypothesise that the web-based system might be especially valuable in case of frequent interventions or consultations in the child's care across complex care networks involving multiple professionals and organisations. In these situations, advanced options such as video consultation services [13] may also be worth considering.

The trial showed that ease of technology use could be improved. Tighter control on system use could be achieved by including automatic feedback or reminders [14]. For optimum integration into daily practice, the system's communication should be linked automatically with existing patient records, something that is difficult to achieve in practice. Depending on the professionals involved, it will take time and effort to realise this.

In clinical use, the system proved to be robust and reliable. The actual system use varied considerably, between parents and professionals. Of the parents and professionals that used the system, 95% and 30%, respectively, found that it was valuable. For successful implementation in clinical practice, however, other aspects are important, such as user adoption and integration into daily health-care practice. Following Rogers' diffusion theory [15] our pilot study reflected the 'innovator' phase and based on the findings we now need to decide whether the service is ready to enter the 'early-adopter' phase. This seems to be the case for parents, but for the professionals it is less clear. Further development of the system for complex cases may be a condition for further diffusion.

According to a staged approach of telemedicine evaluation, early prototypes are evaluated on technical stability and user acceptance, whereas the evaluation of more mature applications focuses on clinical- and cost-effectiveness [12,16]. Thus for the next stage of the present work it is important to focus on clinical outcomes. Financing, policy aspects and legislation should also be addressed. The technical feasibility and positive reactions of the users, although differing between parents and professionals, merit further research into the clinical value of the service.

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CHAPTER 5

DETERMINANTS OF USE AND NON-USE OF A WEB-BASED COMMUNICATION SYSTEM IN CEREBRAL PALSY CARE:

EVALUATING THE ASSOCIATION BETWEEN PROFESSIONALS' SYSTEM USE AND THEIR A PRIORI EXPECTANCIES AND BACKGROUND

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Abstract

Background. Previously we described parents' and professionals' experiences with a web-based communication system in a 6-month pilot in three Dutch cerebral palsy care settings. We found that half of the participating professionals had not used the system, and of those who had used the system one third had used it only once. The present study aimed to evaluate whether professionals' system use was associated with their a priori expectancies and background.

Methods. Professionals who had not used the system (n=54) were compared with professionals who had used the system more than once (n=46) on the basis of their questionnaire responses before the pilot, their affiliation and the number of patients which they represented in the study. The questionnaire items comprised professionals' expectancies regarding the system's performance and ease of use, as well as the expected time availability and integration into daily care practice.

Results. Overall, users had higher a priori expectancies than non-users. System use was associated with expected ease of use (p=.046) and time availability (p=.005): 50% of the users (vs. 31% of the non-users) expected that the system would be easy to use and 93% of the users (vs. 72% of the non-users) expected that they would be able to reserve a time slot each week for responding to submitted questions. With respect to professionals' affiliation, system use was associated with professionals' institution (p=.003) and discipline (p=.001), with more (para-) medical professionals among users (93% vs. 63% among non-users), and more education professionals among non-users (37% vs. 7% among users). In addition, users represented more patients (mean 2, range 1-8) than non-users (mean 1.1, range 1-2) (p=.000).

Conclusions. Professionals' system use was associated with expected ease of use and time availability, professionals' affiliation and the number of represented patients, while no association was found with expected performance of the system. To achieve higher adoption rates in the future, it is important to further develop the technology by optimizing the system's ease of use and interoperability and including advanced consultation options. In addition, better identified end users should be more extensively informed about the system's possibilities through tailored education.

Background

Children with special health care needs (CSHCN) are an important population from health care services, economic and policy perspectives [1]. The CSHCN population involves 'children who have or are at increased risk for a chronic physical, developmental, behavioural, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally' [2]. The broad range of care needs in this population often requires complex and long-term health (related) services from multiple providers across diverse organisations and sectors. In such 'integrated care' settings, inter-professional communication about children's needs, family context, and prior experiences with and responses to health care is essential for effective coordination of services [3]. However, the findings of the U.S. National Survey of CSHCN 2005-2006 revealed that those children most in need of comprehensive, coordinated systems of care were the least likely to receive such care [4]. In addition, a study among CSHCN populations with neurological conditions found that children with multiple conditions had the greatest unmet needs and dissatisfaction with care coordination [5], which was defined in terms of communication among doctors and between doctors and other providers and whether the family received sufficient help coordinating care, if needed. Failure of professionals caring for the same child to communicate with one another often leaves the parents as information intermediaries [6]. This corresponds to our findings on the care of children with cerebral palsy in the Netherlands (see Box 1), in which we identified various gaps in patient care communication, such as lack of patient centeredness and poor inter-professional information exchange, leading to parents acting as messengers of information, as well as to hesitation among professionals to contact each other due to unfamiliarity with those involved in the care network [7]. Although much has been written about the potential of telemedicine to increase access to care, applications in paediatrics are relatively scarce [8]. Nevertheless, they are increasingly being applied to facilitate communication between health care providers and caregivers of paediatric patients with health conditions requiring follow-up [9,10]. Examples include applications using synchronous video-conferencing as the most common mode of communication, and consultation and diagnosis as the most common function [9]. In order to improve parent-professional and inter-professional communication in three Dutch cerebral palsy care settings, we developed an asynchronous, secure web-based communication system aimed at increasing patient centeredness, facilitating inter-professional contact and enhancing network transparency. Previously we described its design features, technical feasibility and clinical usability with respect to its aims, as well as parents'

and professionals' actual system use in a 6-months pilot in three Dutch care regions. We found that half of the participating professionals had not used the system at all and of the professionals who had used the system, a third had used it only once [11]. To enable the development of services with a higher adoption rate it is important to obtain insight into the determinants of use and non-use [12], which might facilitate the definition of user requirements and hence a better fit between user requirements and the system. Functional user requirements generally concern the clinical value/ targeted performance, while non-functional requirements mostly concern ease of use, both of which are considered important determinants of usage intention and subsequent usage behaviour [13,14]. The aim of this study was therefore to evaluate whether professionals' a priori expectancies regarding the system's performance and ease of use were associated with their subsequent use and non-use of the system. In addition, as focus groups convened in the development phase of the project revealed the importance of time availability and integration into daily practice and the role of professional background, these aspects were evaluated as well. The evaluation was performed on user level, comparing professionals who had not used the system (n=54) with professionals who had used the system more than once (n=46), hypothesizing higher a priori expectancies in the use-group. Professional background was evaluated in terms of professionals' affiliation (care region, institution, discipline) and the number of patients that they represented in the study, hypothesizing that professionals in the use-group would represent a higher number of patients.

Box1. Cerebral palsy care in the Netherlands

In the Netherlands, paediatric rehabilitation services are delivered in both inpatient and outpatient settings. The 23 national rehabilitation centres with paediatric facilities and the rehabilitation departments of all medium- sized and larger hospitals offer treatment on an outpatient basis only. For inpatient treatment children can be referred to one of nine specialized, regional rehabilitation centres. Annually, 6,755 children are treated on an outpatient basis and 363 children on an inpatient basis [15]. More than half of these children have been diagnosed with cerebral palsy, an umbrella term for a group of motor disorders which cause activity limitation and are often accompanied by disturbances of sensation, perception, cognition, communication and behaviour, by epilepsy, and by secondary musculoskeletal problems. While its prevalence ranges from 1.5 to 2.5 per 1000 live births with little or no variation among western nations, the importance of cerebral palsy is particularly related to its severity and its consequent burden on affected children, families and societies [16]. Given the broad range of disabilities associated with cerebral palsy, various professionals from diverse organizations are involved in meeting each patient's care needs. In the Netherlands, cerebral palsy patients aged 4-8 years usually are under the supervision of a rehabilitation physician in a (specialized) regional or academic hospital, who often plays a coordinating role in the integral medical care. At the age of 4, the children are referred either to regular schools (whether or not assisted by ambulant supervision) or to schools for special education/ specialized day care centres. Children in regular education can often do with outpatient supervision combined with mono-disciplinary therapy in a primary care centre. Schools for special education usually have close cooperation with the local rehabilitation centre, while specialized day care centres are often supported by ambulant consultation of a rehabilitation physician.

Methods

Study population

To obtain data representative for the integrated care setting of cerebral palsy, the study covered three Dutch care regions ranging from urban to more rural settings. The inclusion of professionals was based on the inclusion of cerebral palsy patients and their parents, which was determined by a rehabilitation physician based on specific selection criteria, which we described in our previous study [11]. Of all the professionals involved in the care of the 30 selected cerebral palsy patients, 120 (67%) were willing to participate in the study. Both parents and professionals gave informed consent after which they received log-in details for system access. System use was on a voluntary basis, i.e. professionals were free in their choice to use the system in a given situation or to apply their usual modes of communication (face-to- face, telephone etc.). The study was conducted in keeping with the protocol of the WMA Declaration of Helsinki. According to Dutch legislation (WMO Medical Research Involving Human Subjects Act) a medical ethics review was not required.

System use and non-use

The system comprised an open access part (a generally accessible website with project related information) and a personalized secured access part with various consultation options. Professionals could contact the parents of the patient(s) whom they represented in the study, as well as colleague-professionals involved in the patient's care network. A detailed description of the system's technical and functional specifications can be found in our previous study [11].

Of the 120 participating professionals, 54 had not used the system during the 6-month pilot (of which 33 did log into the system), 20 professionals had used the system only once and 46 had used it more than once (with a mean of n=6 questions/ responses per professional, sd. 5 and range 2-23). In view of the system's aim to facilitate inter-professional contact, professionals' system use was defined in terms of submitting a question/response in the system more than once. Consequently, trying out the system only once or logging-in without submitting a question/ response was not considered actual system use. The definition of use in terms of using the system more than once was made quite arbitrarily, but with the intention to create a real contrast between the use and non-use group.

Study design

We verified that all 120 participating professionals completed the baseline questionnaire before obtaining access to the web-based system. In table 1 an overview is given of the questionnaire items. Performance expectancy items were derived from the system's aims, which were based on the experienced gaps in communication we previously identified in cerebral palsy care settings [7].

For the majority of items a 5-point Likert-scale was used, ranging from 'no, not at all' to 'yes, definitely' with open text area for clarification. The items on inter-professional communication (i.e. frequency of contact, accessibility of professionals and facilitation of inter- professional consultation) were assessed by means of a scoring table in which professionals could mark their response for each professional involved in their care net- work ('rarely'/ 'occasionally'/ 'regularly' for the item frequency of contact and 'yes'/ 'don't know'/ 'no' for the items accessibility of professionals and facilitation of inter-professional consultation).

Table 1. Questionnaire items evaluating professionals' a priori expectancies of the web-based system

Performance	Frequency of contact *How often do you expect to contact colleague-professionals through use of the system?* Accessibility of professionals *Do you expect that you will be able to reach colleague-professionals more easily through use of the system?* Facilitation of inter-professional consultation *Do you expect that you will be able to consult colleague-professionals more often through use of the system?* Parents' messenger role *Do you expect that as a result of using the system parents less often have to act as messenger of information between professionals?* Consistency of information *Do you expect that as a result of using the system more consistent information can be given to parents?* Transparency of care network *Do you expect that as a result of using the system the child's care network will be more transparent?* (i.e. who is involved from which organization etc.)
Ease of use	*Do you expect that the system will be easy to use for you?*
Time availability	*Do you expect that you will be able to reserve one time slot each week for responding to submitted questions on the system?*
Integration daily care practice	*Do you expect that you will be able to reserve time for system use within your regular working hours?*

The individual scores in each scoring table were recoded into one total score. For the item frequency of contact the total score was 'regularly' when the respondent expected to have regular contact with at least one of his/her colleague-professionals. When this was not the case, the total score was 'occasionally' when the respondent expected to have occasional contact with at least one of his/her colleague-professionals. When the respondent did not expect to have regular nor occasional contact with any of his/her colleague-professionals, the total score was 'rarely'.

For the items accessibility of professionals and facilitation of inter-professional consultation a positive total score ('yes') was given when the respondent expected to resp. reach/consult at least one of his/her colleague-professionals more easily/more often. A negative total score ('no') was given when the respondent did not expect to reach/ consult any of his/ her colleague-professionals more easily/more often. A neutral total score was assigned when the respondent did not know what to expect.

Data analysis

Professionals who had not used the system (n=54) were compared with professionals who had used the system more than once (n=46). Professionals who had used the system only once (n=20) were included in descriptive overviews, but were left out of the statistical analysis in order to create a real contrast between the use and non-use group. For the comparison of professionals' expectancies, Fisher Exact tests (a=.05, df=1) were applied, contrasting the upper response category (positive expectancy scores) with the latter two response categories (neutral and negative expectancy scores), using one-sided p-values in line with our hypothesis that users would have higher expectancies than non- users. For the comparison of professionals' affiliation and the number of patients which professionals represented in the study, Pearson Chi-square tests were applied (a=.05, 2-sided). Given the skewed distribution of the number of represented patients (the majority of professionals participated in the study for only 1 child), it was categorized into an ordinal variable (n=1, n=2 and n≥3).

Results

System use & professionals' a priori expectancies

In table 2 an overview is given of professionals' a priori expectancies in the use and non-use group. As can be seen, both users and non-users had rather high a priori expectancies of the system, although expectancies of users were mostly higher than those of non-users. A statistically significant association was found between system use and expected ease of use (p=.046) and time availability (p=.005): 50% of the users vs. 31% of the non-users expected that the system would be easy to use while 93% of the users vs. 72% of the non-users expected that they would be able to reserve one time slot each week for responding to submitted questions. Although no statistically significant association was found between system use and professionals' expectancies regarding the system's performance, users tended to score higher than non-users.

Table 2. Overview of professionals' a priori expectancies of the system in the use and non-use group

				TOTAL (n=120)		NON-USE (n=54)		USE=1 (n=20)		USE (n=46)		F.Exact (1-sided)
				N	%	N	%	N	%	N	%	
Performance	Frequency of contact	How often do expect to contact colleague-professionals through use of the system?	*regularly*	59	49%	21	39%	15	75%	23	50%	.181
			occasionally	58	48%	32	59%	4	20%	22	48%	
			rarely	3	3%	1	2%	1	5%	1	2%	
	Accessibility of professionals	Do you expect that you would be able to reach colleague-professionals more easily through use of the system?	*yes*	93	78%	39	72%	15	75%	39	85%	.117
			don't know	10	8%	4	7%	4	20%	2	4%	
			no	14	12%	9	17%	1	5%	4	9%	
			missing value	3	3%	2	4%	0	0%	1	2%	
	Facilitation of inter-prof. consultation	Do you expect that you would be able to consult colleague-professionals more often through use of the system?	*yes*	84	70%	37	69%	14	70%	33	72%	.316
			don't know	12	10%	5	9%	4	20%	3	7%	
			no	21	18%	12	22%	1	5%	8	17%	
			missing value	3	3%	0	0%	1	5%	2	4%	
	Parents' messenger role	Do you expect that as a result of using the system parents less often have to act as messenger of information between professionals?	*yes (definitely)*	84	70%	35	65%	16	80%	33	72%	.245
			don't know	30	25%	17	31%	4	20%	9	20%	
			no (not at all)	5	4%	2	4%	0	0%	3	7%	
			missing value	1	1%	0	0%	0	0%	1	2%	
	Consistency of information	Do you expect that as a result of using the system, more consistent information can be given to parents?	*yes (definitely)*	72	60%	30	56%	12	60%	30	65%	.179
			don't know	40	33%	19	35%	7	35%	14	30%	
			no (not at all)	7	6%	5	9%	1	5%	1	2%	
			missing value	1	1%	0	0%	0	0%	1	2%	

(continued) Table 2. Overview of professionals' a priori expectancies of the system in the use and non-use group

				TOTAL (n=120)		NON-USE (n=54)		USE=1 (n=20)		USE (n=46)		F.Exact (1-sided)
				N	%	N	%	N	%	N	%	
Performance	Transparency of care network	Do you expect that as a result of using the system the child's care network will be more transparent?	*yes (definitely)*	65	54%	31	57%	10	50%	24	52%	.468
			don't know	47	39%	19	35%	10	50%	18	39%	
			no (not at all)	6	5%	4	7%	0	0%	2	4%	
			missing value	2	2%	0	0%	0	0%	2	4%	
Ease of use		Do you expect that the system will be easy to use for you?	*yes (definitely)*	48	40%	17	31%	8	40%	23	50%	.046*
			don't know	71	59%	37	69%	12	60%	22	48%	
			no (not at all)	1	1%	0	0%	0	0%	1	2%	
Time availability		Do you expect that you will be able to reserve one time slot each week for responding to questions on the system?	*yes (definitely)*	99	83%	39	72%	17	85%	43	93%	.005*
			don't know	17	14%	11	20%	3	15%	3	7%	
			no (not at all)	4	3%	4	7%	0	0%	0	0%	
Integration into daily care practice		Do you expect that you will be able to reserve time for system use within your regular working hours?	*yes (definitely)*	65	54%	28	52%	12	60%	25	54%	.514
			don't know	19	16%	6	11%	5	25%	8	17%	
			no (not at all)	33	28%	18	33%	3	15%	12	26%	
			missing value	3	3%	2	4%	0	0%	1	2%	

System use & professional background

In table 3 an overview is given of professionals' affiliation (care region, institution, discipline) and the number of represented patients in the use and non-use group. With respect to the professional's care region, the use- group had more professionals from the rural care region C (50% vs. 30% in the non-use group), while the non- use group had more professionals from the urban care region A (39% vs. 22% in the use-group), although this was not a statistically significant association. Comparing the professionals' institution, the use-group had more professionals from rehabilitation centres (39% vs. 13% in the non-use group), whereas the non-use group had more professionals from (special) education/day care centres (56% vs. 24% in the use-group), resulting in a significant association between system use and professionals' institution (p=.003). In addition, system use was associated with professionals' discipline (p=.001): the use-group had more (para-) medical professionals (93% vs. 63% in the non-use group) while the non-use group had more education professionals (37% vs. 7% in the use-group). Comparing the number of patients that professionals represented in the study, users represented more patients (mean 2.0, range 1-8) com- pared to non-users (mean 1.1, range 1-2) (p=.000).

Discussion

The aim of this study was to evaluate whether professionals' use and non-use of a web-based communication system in cerebral palsy care was associated with their a priori expectancies and background. Overall, users had higher a priori expectancies than non-users. System use was associated with expected ease of use and time avail- ability, while no association was found with professionals' a priori expectancies regarding the system's performance. The association with expected ease of use confirms our hypothesis and is conform adoption literature [13,14]. The association with expected time availability is in line with findings in literature reporting providers' concerns that web-based communication would add to their work-load rather than substitute for other tasks [17,18].

Considering the rather high performance expectancies of both users and non-users, one could argue there was little doubt in either of the groups about the expected clinical value of the system, whereas the groups differed in the amount of effort they expected to invest in using the system. Those expecting to have more time available and/or that the system would be easy to use indeed used the system more often.

Table 3. Overview of professionals' affiliation and number of represented patients in the use and non-use group

			TOTAL (n=120)		NON-USE (n=54)		USE=1 (n=20)		USE (n=46)		X^2 (2-sided)
			N	%	N	%	N	%	N	%	
Care region		region A (urban)	35	29%	21	39%	4	20%	10	22%	.079
		region B (urban/ rural)	36	30%	17	31%	6	30%	13	28%	
		region C (rural)	49	41%	16	30%	10	50%	23	50%	
Institution		hospital	22	18%	12	22%	0	0%	10	22%	.003*
		rehabilitation centre	30	25%	7	13%	5	25%	18	39%	
		(special) education/ day care centre	55	46%	30	56%	14	70%	11	24%	
		primary care centre	13	11%	5	9%	1	5%	7	15%	
Discipline	total	medical	23	19%	8	15%	0	0%	15	33%	.001*
		paramedical	66	55%	26	48%	12	60%	28	61%	
		educational	31	26%	20	37%	8	40%	3	7%	
	medical	rehabilitation physician	11	9%	1	2%	0	0%	10	22%	
		paediatrician	8	7%	5	9%	0	0%	3	7%	
		paediatric neurologist	2	2%	1	2%	0	0%	1	2%	
		orthopaedic surgeon	1	1%	1	2%	0	0%	0	0%	
		other	1	1%	0	0%	0	0%	1	2%	

(continued) Table 3. Overview of professionals' affiliation and number of represented patients in the use and non-use group

			TOTAL (n=120)		NON-USE (n=54)		USE=1 (n=20)		USE (n=46)		X^2 (2-sided)
			N	%	N	%	N	%	N	%	
Discipline	paramedical	physiotherapist	31	26%	13	24%	3	15%	15	33%	
		occupational therapist	9	8%	1	2%	3	15%	5	11%	
		speech therapist	6	5%	3	6%	2	10%	1	2%	
		manufacturer rehabilitation aids	4	3%	1	2%	1	5%	2	4%	
		pedagogue	5	4%	3	6%	1	5%	1	2%	
		social work	2	2%	0	0%	1	5%	1	2%	
		orthoptist	4	3%	2	4%	0	0%	2	4%	
		other	5	4%	3	6%	1	5%	1	2%	
	educational	teacher	10	8%	6	11%	3	15%	1	2%	
		(ambulant) supervisor	16	13%	11	20%	4	20%	1	2%	
		group leader (day care)	4	3%	3	6%	0	0%	1	2%	
		other	1	1%	0	0%	1	5%	0	0%	
$N_{patients}$		$N_{patients}$ = 1	94	78%	50	93%	16	80%	28	61%	.000*
		$N_{patients}$ = 2	14	12%	4	7%	2	10%	8	17%	
		$N_{patients} \geq 3$	12	10%	0	0%	2	10%	10	22%	

Comparing these findings with frequently used IT adoption models such as the Unified Theory of Acceptance and Use of Technology [14], the lack of association between system use and professionals' expectancies regarding the system's performance is surprising, as performance expectancy is considered a direct determinant of usage intention and subsequent usage behaviour [14]. The fact that we did not find an association might be related to our operationalization of performance in terms of the aims of the web-based system. Although these system aims were derived from experienced gaps in communication previously identified in cerebral palsy care settings [7], an operationalization in broader terms (i.e. system use would improve my job performance/increase my productivity/make it easier to do my job/ etcetera [14]) might have better addressed the wide range of professionals' outcome expectancies.

With respect to professionals' affiliation, system use was associated with institution and discipline, with more (para-)medical professionals among users and more education professionals among non-users. On the one hand this could imply that the system was of less use to education professionals: their communication with parents usually comprises face-to-face contact, while their inter- professional communication might be less focused on the integrated care network but more on the internal contact within the school/day care centre. On the other hand, they could have had the intention to use the sys- tem, but might not have needed to use it for the particular child they represented in the study, a hypothesis strengthened by the fact that all 31 education professionals who participated did so for only one patient. Indeed, system use was significantly associated with the number of patients which professionals represented in the study: of the professionals who had not used the system the far majority (93%) represented only one patient.

Although professionals' system use was associated with their a priori expectancies and background, the differences between users and non-users were not as pronounced as might be expected. From a methodological point of view, this might be related to the fact that professionals who had not used the system at all were com- pared with professionals who had used the system more than once. This low cut-off point was chosen given the limited range of frequency of use. A clearer contrast between use and non-use and larger population series might have yielded more pronounced differences between both groups.

The evaluation in the present study was performed on the level of individual users and was not focused on the inter-professional and inter-organizational environment that is inherent to integrated care settings such as cerebral palsy. Adoption of innovative technologies that span professional and institutional boundaries pose

challenges in terms of coordination of care processes, such as changing handovers, alignment of objectives and working culture and integrating the technology in each different setting [19]. To ensure that health care technologies are effectively used, an approach is needed that incorporates the complex interdependencies between technology, people and their social-cultural environment [20]. Usually the design and pilot evaluation phases require an interactive process of co-creation and close collaboration with intended users and stakeholders [20], and it will take a while before the technology is sufficiently stable for broad diffusion and interoperable across organizational and social contexts and technical infrastructures [21]. These dynamics are to be taken into account when deciding on an evaluation method. In order to generate usable evidence in the early stages of the fast changing field of telehealth [22], new methodologies such as Constructive Technology Assessment [23] or a holistic approach for the design and evaluation of eHealth technologies [20] can be considered.

Conclusions

For a better understanding of the adoption of telemedicine applications, analysis of determinants of use and non-use is essential. The findings of the present study suggest that users and non-users differ from each other with respect to some of their a priori expectancies, their affiliation and the number of patients that they represented in the study. This information can be taken into account in the further implementation of the system in every day care, but also by making system adaptations in order to increase the chance of professionals' system use. Considering the users' higher expectancies of the system's ease of use, this aspect could be further optimized by reducing the amount of time involved in sys- tem use and providing a better integration of the system in daily care practice by linking the system's communication automatically with existing patient records. As performance expectancies are generally considered a strong determinant of system use, tailored education addressing the broad range of professionals' outcome expectancies may contribute to adoption. With respect to professional background, system use by education professionals might be stimulated through advanced consultation options tailored to their specific needs, provided that the number of patients for which they participate is large enough in order to adequately engage in the system.

In line with a staged approach to telemedicine evaluation, the present study had an explorative character and focused on a limited number of factors that could explain professionals' system use and non-use. Further research may include a more comprehensive evaluation of technology, human and organization issues, in which multivariate analysis can be used to gain insight into the relative contribution of these factors.

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CHAPTER 6

A WEB-BASED COMMUNICATION SYSTEM FOR INTEGRATED CARE IN CEREBRAL PALSY:

EXPERIENCED CONTRIBUTION TO PARENT-PROFESSIONAL COMMUNICATION

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6. CONTRIBUTION TO PARENT-PROFESSIONAL COMMUNICATION

Abstract

Introduction. To improve communication in the integrated care setting of children with cerebral palsy, we developed a web-based system for parent-professional and inter-professional communication. The present study aimed to evaluate parents' experiences regarding the system's contribution to their communication with professionals during a 6-months pilot in three Dutch care regions. In addition, factors associated with parents' system use and non-use were analyzed.

Theory and methods. The system's functional specifications were based on key elements of the Chronic Care Model and quality dimensions formulated by the Institute of Medicine. At baseline, parents completed a T0-questionnaire on their experiences regarding sufficiency of contact, accessibility of professionals, timeliness of information exchange, consistency of information and parents' role as messenger of information and/or care coordinator. After the pilot, parents completed a T1-questionnaire on their experiences regarding the system's contribution to each of these aspects.

Results. Of the 30 participating parents 21 had used the system, of which 20 completed the T1-questionnaire. All these parents indicated that they had experienced a contribution of the system to parent-professional communication, especially with respect to accessibility of professionals, sufficiency of contact and timeliness of information exchange, and to a lesser extent consistency of information and parents' messenger/ coordinator role. In comparison with non-users, users had less positive baseline experiences with accessibility and a higher number of professionals in the child's care network.

Conclusions. All users indicated a contribution of the system to parent-professional communication, although the extent of the experienced contribution varied considerably. Based on the differences found between users and non-users, further research might focus on the system's value for complex care networks and problematic access to professionals.

Introduction

Children with special health care needs (CSHCN) are an important population from health care services, economic and policy perspectives [1]. The often highly specific and heterogeneous care needs in this population require a broad range of long-term care services from multiple providers across diverse organisations and sectors. A primary aim in such inter-disciplinary and inter-organizational settings is to provide integrated and coordinated care across all elements of the health care system and the patient's community [2].

This, however, is increasingly difficult to realize given the high level of differentiation (between professionals, units, organisations) [3] and the resulting complexity of health care, characterized by 'more to know, more to do, more to manage, more to watch, and more people involved than ever before' [4]. Particularly for the rapidly growing population of chronic patients with multiple concurrent conditions, health care organizations often operate as silos, providing care without complete information about the patient's condition, medical history or services provided in other settings [4]. In their report 'Crossing the Quality Chasm', the Institute of Medicine emphasized that health care should be patient-centred, specifying care coordination and integration as one of its key features in order to ensure that accurate information reaches those who need it at the appropriate time [4]. Hereto, effective communication within the health care system and between the health care system and the larger community is of vital importance [4-6] and a fundamental feature in parents' experiencing services as connected or coordinated [7].

In practice however, inadequate communication among health care providers and organizations involved in the child's care is one of the main barriers that challenge care coordination in paediatric services [8]. Based on data of the U.S. National Survey of CSHCN [9], a study among CSHCN populations with neurological conditions found that children with multiple conditions had the greatest unmet needs and dissatisfaction with care coordination, which was defined in terms of communication among doctors and between doctors and other providers and whether the family received sufficient help coordinating care, if needed [10]. Failure of professionals caring for the same child to communicate with one another often leaves the parents as information intermediaries [11] and/ or semi-professional care coordinators [7]. This corresponds to our findings on the care of children with cerebral palsy in the Netherlands (box 1) in which we identified various gaps in communication, such as inadequate cooperation of professionals and an experienced lack of patient-centeredness, as well as insufficient inter-professional contact necessitating parents to take up the role of messenger of information and/ or care coordinator [12].

Box 1. Integrated care for children with cerebral palsy

Cerebral palsy is one of the most severe chronic disabilities in childhood, often making strong demands on health, education and social services as well as on families and children themselves [24]. In the Netherlands, children with cerebral palsy are the largest diagnostic group treated in paediatric rehabilitation [25], with a prevalence ranging from 1.5 to 2.5 per 1000 live births with little or no variation among western nations [26, 27]. Cerebral palsy has usually been defined as an umbrella term covering a group of motor disorders caused by a non-progressive lesion of the immature brain [28]. More recently, activity limitation was added as conditional feature and an annotation was made that the motor disorders are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour, by epilepsy, and by secondary musculoskeletal problems [29]. As no two children are affected in the same way, individual treatment programs vary widely, presenting care providers with heterogeneous and complex diagnostic and therapeutic challenges, requiring a broad range of specialized services from various professionals across diverse institutions and settings [30]. Although one of the primary aims in such interdisciplinary and -organizational settings is to provide integrated care, a study on integrated paediatric services in The Netherlands concluded that despite the fact that family-centred and coordinated care are seen as the two most desirable and effective ways of paediatric care delivery, their practical implementation in Dutch paediatric practice is still in a preliminary stage [31]. In line with this, a descriptive quality inventory of cerebral palsy care in The Netherlands identified suboptimal communication across institutions and settings as one of the main gaps in care coordination [32]. In view of these challenges, the overall aim of our study is to contribute to the improvement of patient care communication across the integrated care setting of cerebral palsy in three Dutch care regions.

Although much has been written about the potential of eHealth technology to stimulate integrated care across patient conditions, services and sites [13-15], applications in paediatrics have been relatively scarce [16]. More recently however, they are increasingly being applied to facilitate communication between health care providers and caregivers of paediatric patients with health conditions requiring follow-up [17, 18]. Based on the identified gaps in three Dutch cerebral palsy care regions (box 2), we aimed to obtain insight in the feasibility and usability of an eHealth application to improve patient care communication in these settings. Hereto, we developed a web-based system for parent-professional and inter-professional communication [19], aimed to increase patient-centeredness, facilitate inter-professional contact and enhance network transparency.

Representing an ‘innovator’ phase [20, 21], early prototypes of eHealth technology are generally evaluated on technical stability and user acceptance [22, 23]. As the system proved to be technically feasible in a 6-month pilot in three Dutch care regions and most parents reported added value in using the system [19], the present study aimed to evaluate parents’ experiences regarding the system’s contribution to

their communication with involved professionals during the 6-months pilot. Hereto, we focused on those aspects of parent-professional communication in which we previously identified gaps and hence were targets of improvement for the web-based system, being sufficiency of contact, timeliness of information exchange, accessibility of professionals, consistency of information and the extent to which parents felt they had to act as care coordinator or messenger of information between professionals.

Box 2. Improving communication in cerebral palsy care

To identify experienced gaps in communication across the integrated care setting of cerebral palsy, we searched the literature for appropriate research methodology. Existing methods though were often restricted to only one aspect of communication (e.g. discharge- or referral communication), one communication link (e.g. general practitioner–hospital specialist) or one evaluation perspective (e.g. the perspective of primary care physicians), or relied solely on quantitative- resp. qualitative methods, thus obtaining either general/population based data or in-depth qualitative data derived from small samples [33]. In view of these shortcomings, we developed a mixed method evaluation approach [33], based on key elements of the Chronic Care Model [6, 34], quality of care aspects formulated by the Institute of Medicine [4] and essential quality dimensions of information(-exchange) [35]. Application of this approach in three Dutch cerebral palsy care regions [12] showed that parents primarily experienced gaps in inter-professional communication, particularly between the (rehabilitation) hospital and primary care physiotherapy resp. (special) education/ day care centre. Subsequent in-depth interviews with a subset of parents showed that the experienced gaps were primarily related to inadequate cooperation of professionals and an experienced lack of patient-centeredness, as well as insufficient inter-professional information-exchange and consistency of information, which often necessitated parents to take up the role of messenger of information or even that of care coordinator [12]. Confronting professionals with these findings yielded further understanding of underlying factors, such as capacity problems and a lack of interdisciplinary guidelines and clear definition of roles, tasks and responsibilities [12].

Based on these gaps in communication, we developed an asynchronous secure web-based system for parent-professional and inter-professional communication, aimed at increasing patient centeredness, facilitating inter-professional contact and enhancing network transparency [19]. For each of these aims, functional specifications were formulated, which were subsequently translated into technical requirements. Based on the findings of a 6-month pilot-evaluation in three Dutch care regions, the system proved to be technically robust and reliable [19]. Approximately two-thirds of the parents and half of the professionals had used the system, of which most parents and some professionals reported to have experienced added value in its use [19], comprising each of the three system aims: patient-centeredness (parents could ask questions at the moment they arose and the whole network could be reached at once, avoiding fruitless phone calls), inter-professional contact (lower threshold for consultation, contact with disciplines which previously were not actively involved in decision making) and network transparency (professionals were being kept up to date between visits, obtaining insight about other professionals' advice; parents could re-view their communication with professionals) [19].

In addition, we aimed to gain insight into factors related to parents' system use and non-use, by comparing parents who had used the system (n=21) with those who had not used the system (n=9) with respect to their baseline experiences with parent-professional communication and the complexity of their child's care network, hypothesizing that users would have less positive baseline experiences and a more complex care network.

Theory and methods

System aims

Following the Chronic Care Model [34], productive interactions between the patient('s family) and involved practice teams arise from essential system changes at the health care organization level, such as self-management support, delivery system design, decision support and clinical information systems [6]. Although eHealth technology has the potential to contribute to each of these system changes [36], changes with respect to self-management support (how to help patients live with their conditions) and delivery system design (who's on the health care team and in what ways they interact with patients) will relatively be most visible to the patient('s family) [6]. As the identified gaps in our study (box 2) particularly reflected improvement needs in these domains, the primary aims of the web-based system were to increase patient-centeredness, facilitate inter-professional contact and enhance network transparency. On page 71 of this thesis an overview is given of these aims and the corresponding design features. In the present study, we focused on the system's aim to increase patient-centeredness and hereto evaluated parents' experiences regarding the system's contribution to their communication with involved professionals during the 6-months pilot.

Study population

In order to obtain data representative for the integrated care setting of cerebral palsy, three Dutch care regions were included ranging from urban to more rural settings. The selection of patients was carried out by a rehabilitation physician, based on files of patients with annual supervision and the following selection criteria: (i) diagnosis cerebral palsy (confirmed by neurologist) and (ii) age between 4-8 years (from the age of 4 diagnosis is mostly clear and (special) education becomes an additional communication partner in the care network). Parents needed to have (i) sufficient Dutch language skills (as judged by the rehabilitation physician) in order to be able to use the communication system and complete questionnaires and (ii) access to the internet as well as basic knowledge how to use it.

Finally, minimal three involved professionals (i.e. the child's rehabilitation physician, (primary care) physiotherapist and professional of (special) education/ day care centre) needed to participate in the study in order to have a sufficient network for communication. On the basis of these criteria, the parents of 30 cerebral palsy patients were included in the study. After completion of informed consent they received log-in data for access to the system. The study was conducted in keeping with the protocol of the WMA Declaration of Helsinki. According to Dutch legislation (WMO Medical Research Involving Human Subjects Act) a medical ethics review was not required.

System use and non-use

System use was on a voluntary basis, i.e. parents were free in their choice to use the system in a given situation or apply their usual modes of communication (face-to-face, telephone etc.). The system comprised an open access part (a generally accessible website with project related information) and a personalized secured access part with various consultation options. Parents could contact professionals in their child's care network, while professionals could contact both parents as well as colleague-professionals involved in the patient's care network. For each submitted question parents had to mark one feedback-responsible professional, an automatic copy was sent to other involved professionals (parents could remove this option if preferred). Information about parents' system use was extracted from the system's database. Of the 30 participating parents, 21 had actually used the system during the 6-months pilot by submitting one or more questions/ and/ or responses to professionals, whereas 9 parents had only logged into the system without submitting a question/response. Considering the system's aim to improve parent-professional and inter-professional communication, system use was defined in terms of submitting a question/response on the system more than once. Consequently, trying out the system only once or logging-in without submitting a question/response was not considered actual system use.

Study design

Baseline questionnaire (T0)

In order to describe the study population and to evaluate parents' experiences with parent-professional communication before the pilot, parents completed a baseline questionnaire, including parent/patient characteristics, frequency and modes of contact with involved professionals in the child's care network and parents' experiences regarding their communication with these professionals, focusing

on sufficiency of contact, timeliness of information exchange, accessibility of professionals, consistency of information and the extent to which parents felt they had to act as care coordinator and/ or messenger of information between professionals. For each of these aspects a scoring table was used in which parents could indicate for each involved professional the extent to which they had experienced sufficient contact/ timely information exchange/ etc. during the preceding 6 months (3-point Likert scale 'usually', 'occasionally' or 'rarely').

Questionnaire after 6-month pilot (T1)

After the pilot parents completed a questionnaire on the experienced contribution of the system to each of these aspects of parent-professional communication. In addition, parents were asked whether they less often needed face-to-face/ telephone contact with involved professionals as a result of using the system. For the items sufficiency of contact, timeliness of information exchange and accessibility of professionals, the experienced contribution was evaluated by means of scoring tables in which parents could indicate for each involved professional the extent to which they had experienced a contribution of the system (3-point Likert scale 'considerably', 'to some extent' or '(hardly) not'). For the items consistency of information and the coordinator/ messenger role, detailed evaluation per professional was considered less appropriate given the inter-dependency among professionals that is inherent to these aspects of parent-professional communication. Therefore instead of using scoring tables, the experienced contribution for these items was evaluated by means of a 5-point Likert-scale (ranging from 'yes, definitely' to 'no, not at all').

Data analysis

Parents' questionnaire responses T0/ T1

Parents' T0 questionnaire responses were listed in an overall table, indicating for each parent the proportion of professionals that were scored with a positive/ intermediate/ negative response (resp. 'usually'/ 'occasionally'/ 'rarely', see table 1). As such, the intermediate and negative responses represented experienced shortcomings in parent-professional communication and thus targets for improvement of the communication system.

Parents' T1 questionnaire responses on the items sufficiency of contact, timeliness of information exchange and accessibility of professionals were listed in an overall table, indicating parent's responses regarding the experienced contribution of the system for each involved professional that participated in the study ('considerably', 'to some extent'/ '(hardly) not', see table 3).

Factors associated with parents' system use & non-use

To evaluate whether parents' system use was associated with their baseline experiences regarding parent-professional communication, the T0-questionnaire responses of parents who had used the system (use-group, n=21) were compared with the responses of parents who had not used the system (non-use group, n=9), focusing on the proportion of professionals that were scored with a positive experience on the concerning aspect of parent-professional communication (see table 1). Given the skewed distribution of these proportions, non-parametric tests for independent samples were applied (Mann-Whitney, α=.05), using one-sided p-values in line with our hypothesis that the use-group would have less positive baseline experiences with parent-professional communication and thus the proportion of professionals that were scored with a positive experience was expected to be lower than in the non-use group. In addition, we evaluated whether the complexity of the child's care network was associated with parents' system use, by comparing the amount of involved professionals and institutions between the use and non-use group. For this comparison independent-sample t-tests were applied (α=.05), using one-sided p-values in line with our hypothesis that the amount of involved professionals and institutions would be higher in the use-group than in the non-use-group.

Results

Parents' baseline experiences (T0)

Table 1 summarises parents' responses at baseline, both for the parents who had used the system (use, n=21) and the parents who had not used it during the 6-month pilot (non-use, n=9). The numbers represent the number of professionals that were marked with a positive (white label), intermediate (grey label) or negative response (black label). As can be seen in the vertical total scores, the majority of professionals were marked with a positive response, although the proportion of positive responses differed between the items, ranging from 88% for consistency of information to 57% for parents as messenger of information. However, looking horizontally at the individual parent level, each parent had scored intermediate or negative responses on one or more items. A relatively high proportion of parents indicated that they had to act as care coordinator or messenger of information: resp. 21 out of 29 parents (72%) and 22 out of 28 parents (79%) had scored one or more professionals with an intermediate and/ or negative response. Of the professionals that were marked with a negative response (n=26), the majority were medical specialists (n=14) and paramedical therapists in (special) education-/ day care centres (n=8).

Table 1. Parents' baseline experiences regarding parent-professional communication

		Sufficiency	Timeliness	Accessibility	Consistency	Coordinator	Messenger
		With this professional I [.....] had sufficient contact	*With this professional I [.....] had timely information exchange*	*This professional was [.....] accessible for consultation*	*Of this professional I [.....] received consistent information*	*With this professional I [.....] felt I had to act as care coordinator*	*With this professional I [.....] felt I had to act as messenger of information*
Parent		$N_{professionals}$	$N_{professionals}$	$N_{professionals}$	$N_{professionals}$	$N_{professionals}$	$N_{professionals}$
USE (n=21)	1	5 | 1	4 | 2	3 | 1 | 1	5 | 1	3 | 2	1 | 5
	2	7 | 2	9	9	8	5 | 3	4 | 3
	3	10 | 2	12	12	12	7 | 5	6 | 6
	4	4	4	4	4	4	3
	5	1 | 4	5	2 | 3	5	5	1
	6	9 | 3	10 | 1	7 | 1	4	7	3
	7	8 | 4 | 1	9 | 1	2 | 7	4	3 | 4	10
	8	6 | 3	5 | 2	6	6	3 | 2 | 1	1
	9	4 | 3	3 | 2	5 | 2	6	4 | 3	3 | 1
	10	3 | 2	1 | 1	3 | 1	4	3 | 1 | 1	2
	11	5 | 3 | 3	1 | 7 | 3	1 | 9 | 2	10 | 1	11	11
	12	14	14 | 1	14 | 1	15	10 | 1	14
	13	8 | 1	9	7 | 1	9	8 | 1	5 | 2
	14	6 | 2 | 1	3 | 3	2 | 3	X	2 | 2	5
	15	6 | 1	7	4 | 2	7	7	6
	16	2 | 2	2	3 | 2	1	1 | 1	X
	17	6	6	3 | 1	X	X	2
	18	11 | 1	12	3 | 9	12	12	10 | 1
	19	4 | 3	3 | 1	4	4	4 | 1	2 | 1 | 1
	20	4 | 2	4 | 1	4 | 1	X	1 | 1 | 2	1 | 1 | 1
	21	6	5	3 | 1	3 | 1	1 | 4	5

	= 'usually'		= 'rarely'
	= 'occasionally'		= 'occasionally'
	= 'rarely'		= 'usually'
X	= missing value	X	= missing value

(continued) Table 1. Parents' baseline experiences regarding parent-professional communication

		Sufficiency	Timeliness	Accessibility	Consistency	Coordinator	Messenger
		With this professional I [.....] had sufficient contact	*With this professional I [.....] had timely information exchange*	*This professional was [.....] accessible for consultation*	*Of this professional I [.....] received consistent information*	*With this professional I [.....] felt I had to act as care coordinator*	*With this professional I [.....] felt I had to act as messenger of information*
Parent		$N_{professionals}$	$N_{professionals}$	$N_{professionals}$	$N_{professionals}$	$N_{professionals}$	$N_{professionals}$
NON-USE (n=9)	22	7	5	6	6	6	2
	23	8 | 3	5 | 5	8 | 3	4 | 4	5 | 2	4 | 2
	24	5	3 | 1	5	5	5	5
	25	5	5	4 | 1	4 | 1	5	3 | 1
	26	3 | 3	4 | 1 | 1	3 | 3	4 | 1	2	1 | 4
	27	4 | 2	8	8	X	4 | 4	X
	28	8	7 | 1	5	8	5 | 3	5 | 1
	29	4 | 6 | 2	6 | 4	10	6 | 1 | 1	2	6
	30	7 | 1	6 | 2	8	3 | 2	3 | 3	3
TOTAL	$N_{professionals}$	**176** | **55** | **10**	**177** | **31** | **9**	**158** | **48** | **7**	**151** | **19** | **2**	**126** | **42** | **17**	**88** | **47** | **19**
	%	**73%** | **23%** | **4%**	**82%** | **14%** | **4%**	**74%** | **23%** | **3%**	**88%** | **11%** | **1%**	**68%** | **23%** | **9%**	**57%** | **31%** | **12%**
	$\%_{parents}$	**73%** (n=22)	**57%** (n=17)	**63%** (n=19)	**38%** (n=10)	**72%** (n=21)	**79%** (n=22)
		= *'usually'* = *'occasionally'* = *'rarely'* X = missing value				= *'rarely'* = *'occasionally'* = *'usually'* X = missing value	

Parents' system use during the 6-month pilot

Of the 30 participating parents, 21 parents had actually used the system, submitting n=111 questions and n=59 responses, with a mean of 5 questions (range 1-17) and 3 responses (range 1-9) per parent. As can be seen in table 2, the rehabilitation physician was most frequently marked as feedback-responsible professional (41% of the 111 submitted questions), next to the physiotherapist and occupational therapist (respectively 20% and 14% of the 111 submitted questions).

Table 2. Overview of feedback-responsible professionals in parents' submitted questions (n=111).

			Questions	
			N	%
Care region		region A (urban)	34	31%
		region B (urban/rural)	16	14%
		region C (rural)	61	55%
Institution		hospital	27	24%
		rehabilitation centre	48	43%
		(special) education/ day care centre	19	17%
		primary care centre	17	15%
Discipline	total	medical	49	44%
		paramedical	51	46%
		educational	11	10%
	medical	rehabilitation physician	45	41%
		paediatrician	3	3%
		paediatric neurologist	1	1%
	paramedical	physiotherapist	22	20%
		occupational therapist	15	14%
		manufacturer rehab.aids	5	5%
		speech therapist	2	2%
		social work	2	2%
		orthoptist	2	2%
		pedagogue	1	1%
		dietician	1	1%
		creative therapist	1	1%
	educational	teacher	8	7%
		(ambulant) supervisor	2	2%
		group leader (day care)	1	1%

Overall, (para-)medical professionals were feedback-responsible for the far majority of parents' questions (90%), whereas education professionals were addressed for feedback in only 10% of the submitted questions.

Experienced contribution of the system (T1)

Of the 21 parents that had used the system, 20 completed the T1-questionnaire. Table 3 shows their responses regarding the experienced contribution of the system to respectively sufficiency of contact (s), accessibility of professionals (a) and timeliness of information exchange (t) for each involved professional that participated in the system's pilot. As can be seen in the overall scores at the bottom of the table, all 20 parents that completed the T1-questionnaire indicated that for one or more involved professionals the system had -to a greater or lesser extent- contributed to sufficient contact, accessibility and/ or timely information exchange. In total 14 parents indicated that the system had 'considerably' contributed to sufficient contact with one or more involved professionals, particularly the rehabilitation physician (indicated by 10 parents) and the physiotherapist (5 parents). With respect to accessibility and timely information exchange, in total 13 parents indicated a considerable contribution of the system, again particularly for the rehabilitation physician (indicated by resp. 8/ 9 parents) and the physiotherapist (indicated by resp. 9/ 10 parents). As can be further seen in the table, the number of times that professionals were marked as feedback-responsible for a submitted question (N_{total}=111) was related to the experienced contribution of the system. For those professionals that had not been marked as feedback-responsible for a submitted question (N=0), parents mostly did not experience a contribution of the system. On the other hand, the table shows that even when a professional was only marked once as feedback-responsible for a submitted question (N=1), various parents indicated that they had experienced a considerable contribution of the system for that particular professional.

Considering parents' responses regarding the experienced contribution of the system to consistency of information and parents' messenger/ coordinator role, less than half of the 20 parents (n=9) indicated a positive response on these items (10%-25% did not know and 25%-35% indicated a negative response).

Table 3. Parents' responses regarding the experienced contribution of the system to sufficiency of contact (s), accessibility of professionals (a) and timeliness of information exchange (t)

T1	Region A						Region B						Region C								
	parent 1	parent 2	parent 3	parent 4	parent 5	parent 6	parent 7	parent 8	parent 9	parent 10	parent 11	parent 12	parent 13	parent 14	parent 15	parent 16	parent 17	parent 18	parent 19	parent 20	parent 21
Hospital	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N
rehabilitation physician	8	1	0	4	0	2		2	0		4	0									
paediatrician								2			0			0	1				0		0
paediatric neurologist			0												0				1		0
orthopaedic surgeon																				0	0
physiotherapist				0																	
occupational therapist				0																	
orthoptist						0	0							2			0				
other															1						
Rehabilitation centre	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N
rehabilitation physician		2	0			0	2					0	6	6	1	1	2	1	0	3	0
physiotherapist			4			0					0	0	2	0		0	2	2			
occupational therapist			2									1	0	1	3	1	0	0			
speech therapist												0									
social work														0			2				
creative therapist													1					0			
School/ day care centre	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N
physiotherapist							0	1				0			2				0		
occupational therapist					2																
speech therapist					0		2								0						
pedagogue					0			0		X 1				0	0		0	0			
teacher	0			1			0				0						0	7			0
ambulant supervisor	0	0							0					0							
internal supervisor	0			1			0		0				0	1							
group leader (day care)								0							1						
other	0			0			0	0				0									
Primary care centre	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N
physiotherapist	1	0			0	3			1					2				0		0	2
occupational therapist								0						5							
manufacturer rehab. aids	0	0	0	0		3			0		0	0	2	0						0	0
other													0								
	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N	s a t N
Overall	9	3	6	6	2	8	4	5	1	X 1	4	1	11	17	9	2	6	10	1	3	2

s parents' responses regarding the experienced contribution of the system to **sufficiency** of contact

a parents' responses regarding the experienced contribution of the system to **accessibility** of professionals

t parents' responses regarding the experienced contribution of the system to **timeliness** of information exchange

*system use **considerably** contributed to sufficiency of contact/ accessibility of professionals/ timeliness of information exchange*

*system use **to some extent** contributed to sufficiency of contact/ accessibility of professionals/ timeliness of information exchange*

*system use **(hardly) not** contributed to sufficiency of contact/ accessibility of professionals/ timeliness of information exchange*

N number of times that the parent marked this professional as feedback-responsible for a submitted question

Factors associated with parents' system use and non-use

Comparing the 21 parents who used the system with the 9 parents who had not used the system, the non-users scored relatively higher at baseline on accessibility of professionals: 89% of the professionals were marked with a positive experience on this item, compared to 68% for the users, a statistically significant difference (p=.023). With respect to parents' baseline experiences regarding sufficiency of contact, both groups scored nearly the same (in the non-use group 75% of the professionals were marked with a positive response on this item, compared to 72% in the use-group). For the remainder of the items, the use-group scored higher than the non-use group, although no significant differences were found.

Comparing the complexity of the child's care network between both groups, the mean number of involved professionals in the use-group was 8.3 (range 5-14) compared to 5.7 (range 3-10) in the non-use group, a statistically significant difference (p=.006). The mean number of involved institutions was higher in the use group (mean 4.1 range 2-7) compared to the non-use group (mean 3.7 range 2-5), although this was not a significant difference.

Discussion

Although the rationale for integrated care is often approached from a system/-organisational perspective in terms of efficiency and cost-effectiveness, the patient-centred imperative and meaning is of increasing importance [17]. In order to improve parent-professional and inter-professional communication in the integrated care setting of children with cerebral palsy, we developed a web-based communication system aimed at increasing patient centeredness, facilitating inter-professional contact and enhancing network transparency. The aim of this study was to evaluate parents' experiences regarding the system's contribution to their communication with involved professionals. Based on previous findings [12], the system was expected to contribute to sufficient contact, timely information exchange, accessibility of professionals and consistency of information, as well as to decrease the need for parents to act as care coordinator and messenger of information between professionals.

Of the 30 parents that participated in the 6-months pilot, 21 had used the system. At baseline, all of them generally experienced good communication with the majority of professionals, but each parent also experienced gaps on one or more aspects, especially sufficiency of contact, accessibility of professionals and the coordinator-/messenger role. This corresponds with findings in literature, in which parents reported being the only coordinators of care for their children or the primary method

of communication between physicians [7, 11]. Of the 20 users that completed the T1 questionnaire, all had experienced a contribution of the system on one or more aspects. The majority of parents indicated to have experienced a contribution of the system on sufficiency of contact, timely information exchange and accessibility of professionals, whereas consistency of information and the extent to which parents feel care coordinator or messenger of information seemed less influenced by the system. The higher experienced contribution on sufficiency, timeliness and accessibility could be due to a more direct impact of the system on these items, whereas the other aspects might be more dependent on other modes of communication (face-to-face/ telephone contact) as well, each affecting consistency of information and the extent to which parents feel care coordinator/ messenger of information. Improvement of these aspects might be stimulated through parent-professional discussion of these issues, in which parents are given choices about their role in communicating information between professionals [11].

From a methodological point of view, the differences in experienced contribution could also be due to the fact that the items sufficiency, timeliness and accessibility were assessed by means of a scoring table (in which experienced contribution was operationalized on the level of individual professionals), whereas the system's contribution to the other items were assessed in more general terms by means of a 5-point Likert scale in which parents could only give overall scores. The choice for a more generic evaluation for these items was made after analysis of parents' responses in the baseline questionnaire, in which detailed evaluation per professional turned out to be less appropriate considering the inter-dependent nature inherent to these aspects of parent-professional communication.

Although all users had experienced a contribution of the system on one or more aspects, the extent of the experienced contribution varied considerably: some parents experienced a contribution on only one aspect and for just one or two involved professionals, while other parents experienced a contribution on more aspects and for various professionals. This might be partly explained by parents' differing baseline experiences, but another factor might be the broad variation in frequency of system use (with a mean of n=8 questions/responses per parent, sd. 6 and range 2-20). Parents who used the system more frequently might be more likely to have experienced a contribution of the system, although our findings showed that just one submitted question could also positively contribute to parent-professional communication.

Considering the applied methodology to evaluate parents' experiences, the choice for detailed scoring tables was made in order to evaluate parents' experiences for each involved professional, and thereby to detect potential disciplines for whom the web-based system might have particular added value. Based on the findings in the present study, this seemed to be the case for the rehabilitation physician and the physiotherapist, whom parents frequently marked as feedback-responsible professionals in submitted questions, and for whom parents experienced a considerable system contribution to sufficient contact, accessibility and/ or timely information exchange. However, the reliability of parents' responses was suboptimal, as could be seen in the total number of marked professionals in the baseline questionnaire item. A more overall quantitative measure or qualitative evaluation might have additional value, although the possibility to detect changes per professional might have been lost.

Of the participating parents, almost one third had not used the system. At baseline, these parents scored significantly higher on accessibility of professionals, which might partly explain their non-use of the system: they already could reach their professionals relatively easily. In these situations of good accessibility of professionals, a web-based system might therefore be less indicated. In line with this, we found that the complexity of the care network (measured by means of the amount of involved professionals and institutions) was higher in the use-group than in the non-use group. Based on the differences found between the use- and non-use group, we hypothesize that the system may be especially valuable in patient populations with complex care networks involving multiple professionals and institutions, and less positive experiences with accessibility of professionals.

Conclusions

All users experienced a contribution of the system to parent-professional communication, although the extent of the experienced contribution varied considerably. The strength of the system appears to lay in its contribution to sufficient contact, timely information exchange and accessibility of professionals, whereas consistency of information and the coordinator/ messenger role seemed less influenced by the system. In line with a staged approach of telemedicine evaluation, these findings can be taken into account in the further development of the system, ranging from optimization of the system by expanding consultation possibilities and providing insight into the consultation process, to a more specific definition of the system's target population, focusing on patient populations with complex care networks and problematic access to professionals. In addition, innovative methods

such as social network analysis might be applied to gain insight in the strength of parent-professional and inter-professional relationships as a proxy for success in integrated care [37].

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CHAPTER 7

GENERAL DISCUSSION

Objective

The aim of this thesis was to contribute to the improvement of patient care communication across the integrated care setting of cerebral palsy in the Netherlands. For this purpose, two subsequent phases have been followed. In the first phase of the study, the focus was on identifying experienced gaps in parent-professional and inter-professional communication across the cerebral palsy setting in three Dutch care regions. Hereto, a three-step mixed method evaluation approach was developed and applied in each of the three care regions. In the second phase, the focus was on the development of a web-based communication system and obtaining insight in its feasibility and usability to improve parent-professional and inter-professional communication in each of the three care regions. In this final chapter we discuss the main findings of both phases, as well as their implications for research aimed at improving patient care communication across integrated care settings like cerebral palsy. First we reflect on the identified gaps in communication and the applied evaluation methodology. Subsequently we discuss the feasibility and usability of the web-based system, reflecting on its value as an improvement strategy for the identified gaps in communication. Finally, we end this chapter with our main conclusions and recommendations for further research.

Experienced communication gaps in cerebral palsy care

Main findings & implications

In order to identify experienced communication gaps in cerebral palsy care, we performed a literature search to find an adequate methodology for evaluating patient care communication across diverse organisational settings. We found that existing methods were often restricted to only one aspect of communication (e.g. discharge- or referral communication), one communication link (e.g. general practitioner–hospital specialist) or one evaluation perspective (e.g. the perspective of primary care physicians). Moreover, most studies relied solely on either quantitative- or qualitative methods, thus obtaining either general/ population based data, or in-depth qualitative data derived from small samples. In view of these shortcomings, we developed a three-step mixed method evaluation approach, which we subsequently applied in the cerebral palsy setting in each of the three care regions.

The first step's parent questionnaire showed that parents primarily experienced gaps in inter-professional communication, particularly in the communication between the (rehabilitation) hospital and the primary care setting.

Subsequent in-depth interviews with a subset of parents showed that the experienced gaps were primarily related to inadequate cooperation of professionals and a lack of patient-centeredness, as well as insufficient inter-professional information-exchange and consistency of information. As a result, parents regularly had to take up the role of messenger of information or even that of care coordinator, which corresponds to various findings in literature [1-4]. Confronting professionals with these findings as a final step, yielded recognition and acknowledgement as well as a further understanding of underlying factors. The experienced lack of cooperation and patient-centeredness between the (rehabilitation) hospital and (special) education/ day care centre was primarily attributed to a lack of interdisciplinary guidelines and clear definition of roles, tasks and responsibilities. This is in line with findings of Nijhuis et al. (2007) who emphasized the need for protocols that specify commitments for collaboration and provide practical and detailed guidelines as a prerequisite for successful teamwork [5]. The experienced lack of inter-professional information-exchange between the (rehabilitation) hospital and primary care professionals was primarily attributed to capacity problems, which corresponds with findings of Gupta et al. (2004) who identified lack of time and medical staff as the two most frequently reported barriers to provide paediatric care coordination [6]. In addition, professionals also indicated a certain hesitance for contact due to unfamiliarity with other involved professionals in the child's care network. This corresponds with findings of Anthony (2003), according to whom direct communication between health professionals is stimulated by the existence of informal relationships [7].

Overall, the three subsequent steps revealed gaps with respect to aspects of inter-professional information exchange (such as sufficiency of contact, consistency of information, parents' messenger role) as well as organization of care (such as capacity, interdisciplinary guidelines, definition of roles), in which aspects of the latter were identified as underlying factors of the first. This is also reflected in the Chronic Care Model [8], which states that 'productive interactions' between patients and involved practice teams arise from essential system changes at the health care organization level [9]. These system changes can involve self-management support (how to help patients live with their conditions), delivery system design (who's on the health care team and in what ways they interact with patients), decision support (what is the best care and how it can be realized in daily care practice) and clinical information systems (how to capture and use critical information for clinical care) [9]. Since eHealth technology has the potential to contribute to each of these system changes [10], the focus of the second phase of our study was on obtaining insight in the feasibility and usability of an eHealth application to improve patient

care communication across the cerebral palsy care setting. System changes with respect to self-management support and delivery system design will relatively be most visible to the patient/ family [9] and the identified gaps in the first phase of our study particularly reflected improvement needs in these domains. Therefore the second phase of our study comprised the development and pilot-evaluation of a web-based system for parent-professional and inter-professional communication, aimed at increasing patient centeredness, facilitating inter-professional contact and enhancing network transparency.

Methodological considerations

The three-step mixed method approach that was used to evaluate experienced gaps in patient care communication comprised a quantitative identification of relevant cases (step I) for subsequent qualitative in-depth evaluation (step II and III). Although a drawback of such a 'sequential explanatory design' is the amount of time involved in data collection [11], its main strength is its straightforward implementation, as the subsequent steps fall into clear separate stages [11]. In addition, a mixed design offers the possibility to obtain a more complete picture of the research problem through triangulation of data, both between the first two steps (in-depth exploration of relevant cases) and the last two steps (confirmation, cross-validation and corroboration of findings from the perspective of parents and professionals).

In order to do so, we applied an analytic framework covering essential aspects for integrated care, based on key elements of the Chronic Care Model [8, 9, 12], quality of care aspects formulated by the Institute of Medicine [13] and relevant quality dimensions of information (-exchange) [14]. As the identified gaps in the first phase of our study showed difficulties to provide care services as coherent and linked over time, a potential useful addition to our analytic framework might be the concept of 'continuity of care'. Although definitional, conceptual and measurement issues have complicated research on this concept [15, 16], continuity of care is generally considered as the combined result of 'informational continuity' (the use of information on past events and personal circumstances to make current care appropriate for each individual), 'relational continuity' (an ongoing therapeutic relationship between a patient and one or more providers) and 'management continuity' (a consistent and coherent approach to the management of a health condition that is responsive to a patient's changing needs) [16, 17].

The correspondence of these aspects with the identified gaps in our study (insufficient inter-professional information exchange, lack of patient-centeredness, inadequate cooperation etcetera) merit further research into their potential value in evaluating

patient care communication across integrated care settings like cerebral palsy. Although the evaluation of continuity of care from the perspective of parents of children with chronic health conditions has been a relatively under-explored research area [3], recent work of Miller et al. (2009) confirmed that evaluating this concept indeed might be promising. They not only demonstrated that informational, relational and management continuity were analytically useful in evaluating parents' experiences with their child's care, but also showed dynamic interdependencies among the three types of continuity, such as the importance of a thorough knowledge of the child through ongoing relationships as well as meaningful and effective communication across settings and sectors [3].

Feasibility and usability of a web-based communication system

Main findings and implications

In the care of children with special health care needs (CSHCN), eHealth applications are predominantly synchronous ('real time'), with video-conferencing as the most common mode of communication, and consultation and diagnosis as the most common function [18]. In order to realize coordination and integration of care, the use of asynchronous ('store and forward') applications that span the whole care network is of vital importance, though as yet underexposed in CSHCN patient populations such as cerebral palsy. Hereto, we developed an asynchronous secure web-based system for parent-professional and inter-professional communication, aimed at increasing patient centeredness, facilitating inter-professional contact and enhancing network transparency.

Based on the findings of the 6-month pilot-evaluation in which the parents of 30 cerebral palsy patients and 120 involved professionals participated, the system proved to be technically robust and reliable. Approximately two-thirds of the parents and half of the professionals had used the system, of which most parents (95%) and some professionals (33%) reported to have experienced added value in its use. This added value comprised each of the three system aims: increased patient-centeredness (parents could ask questions at the moment they arose and the whole network could be reached at once, avoiding fruitless phone calls), facilitation of inter-professional contact (such as a lower threshold for consultation, contact with disciplines which previously were not actively involved in decision making) and enhanced network transparency (for instance professionals were being kept up to date between visits, obtaining insight about other professionals' advice; parents could re-view their communication with professionals).

Improvement suggestions were related to the system's ease of use and its integration

into daily practice, as well as its fit with the target population. Regarding this latter aspect, it was suggested that the system might be more valuable in younger age categories (early intervention period 0-4 years), given the frequently required consultations for diagnosis, in which various professionals across diverse settings are involved. This is in line with recent literature on best practices in early childhood intervention [19, 20], which emphasizes the need for family-centred, coordinated, and integrated services in order to meet the complex needs of children with disabilities and their families especially in this early intervention phase. As we also found that parents' system use was associated with the number of involved professionals in the child's care network, we hypothesized that the system might be of particular value in case of frequent interventions and/ or consultations across complex care networks involving various professionals from diverse organizations. Translated to practice, this might imply that a particular subgroup of parents could be given the opportunity to use the system during a specific time-period, for example after Botox treatment and/ or orthopaedic surgery, in which clear communication between members of the team and the family is desirable [21, 22]. As the primary care provider, the rehabilitation physician might have a signalling role in considering whether a child's care situation might benefit from additional consultation.

As the 6-month pilot showed that almost half of the participating professionals had not used the system at all, and of those who had used the system one third had used it only once, we evaluated whether professionals' system use was associated with their a priori expectancies and background characteristics. We found that system use was associated with expected ease of use and time availability, i.e. those expecting to have more time available and/ or that the system would be easy to use, indeed used the system more often. In addition, we found that professionals' system use was associated with their affiliation (with more (para-) medical professionals among users and more education professionals among non-users) and the number of patients they represented in the study (users represented more patients than non-users). In order to achieve higher professionals' adoption rates in future, these findings suggest the importance of a further development of the technology as well as a better identification of (the needs of) relevant end users.

With respect to the latter, the system's value for education professionals might be considered more closely. Their relative large proportion of non-users could imply that the value of the system was either not clear to them or they judged it to have insufficient value. This might be related to the fact that their communication with parents usually comprises face-to-face contact, while their inter-professional communication might be more internally focused within the school/ day-care centre.

Otherwise, education professionals could have had the intention to use the system, but might not have needed to use it for the particular child they represented in the study. This hypothesis is strengthened by the fact that all education professionals who participated, did so for only one child and professionals' system use was positively related to the number of patients that they represented in the study. Translated to practice, this might imply that system use by education professionals could be stimulated through tailoring the system to their specific communication needs, ensuring that the number of patients for which they use the system is large enough to adequately engage in the system.

With respect to the technology, the system's design features were primarily focused on facilitating low-threshold parent-professional and inter-professional contact. Although this basic functionality remains essential, further development of the technology could include more advanced consultation options such as video consultation services [23] and/ or (links to) social media applications [24]. These options might be provided in the form of diverse system modules, which could be used separately or in combination with each other, dependent on the specific user needs. An example of such a combination of various resources and consultation services into one system is the Comprehensive Health Enhancement Support System (CHESS™), an umbrella name for a variety of eHealth programs, which recently has been applied in paediatric care settings as well [25] and aimed to enable a broad variety of services tailored to specific parent-professional and inter-professional consultation needs. In addition to incorporating diverse consultation modules within the web-based system, its ease of use could also be further optimized, for example by adding quick links on the website's home page and simplifying log-in procedures. A better integration of the system in daily care practice could be realized by automatically linking the system's communication to existing patient records. Whereas the establishment of inter-organizational communication networks to exchange patient data often faces major interoperability problems [26, 27], a system-hyperlink in a child's electronic record would be a feasible alternative, providing direct access to the preceding web-based communication regarding that child's care.

Overall, the 6-month pilot showed that the system was technically feasible and that the majority of the parents and a relative minority of involved professionals experienced added value from its use. In order to advance the system's implementation in practice, it is thus advisable to invest in further development of the technology as well as to better identify the (needs of the) target population. As the findings of our study indicate that the system might be of particular value in case of frequent consultations across complex care networks, it might be considered to link the

system to early intervention initiatives for complex care settings in the Netherlands [28, 29]. Recently in the U.S. a closely similar initiative was started [30] in which an online communication resource for families of CSHCN populations is embedded in the organizational setting of a primary care medical home. Research on this project has to prove whether this confirms our findings and suggestions. Apart from clarifying these content- and organisation related issues, in the next diffusion phase budget impact and cost effectiveness analyses are needed to estimate the chances of broader diffusion of this technology.

Methodological considerations

For the system's development an iterative design was applied, integrating parents' and professionals' feedback through interactive information meetings and helpdesk correspondence. As such, parents and professionals were actively involved in both the system's design and pilot-implementation, which is one of the key features of user-centred design cycles [31]. However, the large differences in system use between parents and professionals indicate that the system's fit to user needs could be improved upon. In addition to user-centred design and evaluation models focusing on the needs of individual end-users, Nijland et al. (2011) emphasized the need for a more value-driven approach in early stages of development in order to create sustainable eHealth technologies [32]. Hereto, they recommend a business modelling process in which all relevant stakeholders articulate each other's critical factors for the eHealth technology; this has the objective to create a 'fit-for-all' solution in the form of a business model, that describes how the technology will create value for all relevant stakeholders and determines which functionalities are important to develop (as they add the most value)- and which not [32]. Furthermore, they propose a holistic framework for the development of eHealth technologies in healthcare [32], which starts before technology is mentioned at all by means of a 'contextual inquiry' focused on problem identification (what is the problem? why is eHealth technology needed?) and stakeholder analysis (who is involved? who has a stake in addressing the problem?). Although these questions were to some extent addressed in the first phase of our study, a more explicit contextual inquiry at the start of the second phase of our study might have yielded more insight in the relative importance of the various identified problems as experienced by each of the various involved stakeholders. This could have contributed to a better fit between the system's functionalities and its end users and thereby a potentially increased uptake of the system.

With respect to the system's design specifications, our focus was primarily on the system as a 'product', specifying its aims and corresponding functional and technical

requirements, which formed the basis for the system's prototype.
In a more service-directed socio-technical approach, the primary focus is on the interrelation between the technology and its social environment, recognizing that technology implementation is above all a matter of organizational change [33, 34]. This requires a thorough insight into the work practices in which the technology will be used, in order to be able to optimize their fit and tackle interoperability problems [35, 36]. This would imply a more in-depth process analysis parallel to the evaluations we performed. In complex care settings such as cerebral palsy, this however would be a laborious exercise, considering the numerous involved professionals across diverse organizations and sectors. In such settings, a collaborative design process in the form of a multi-disciplinary thematic seminar [37] or defining future diffusion scenarios [38] might be considered. This can be a way to interactively identify relevant design and service factors that can both extend beyond what professionals consider feasible considering their actual practice and likely in view of present or perceived features of the system.

Conclusions and recommendations

By identifying experienced gaps in communication and the subsequent development of an improvement strategy in the form of a web-based communication system, this thesis contributed to the improvement of patient care communication across the integrated care setting of cerebral palsy in three Dutch regions. The system's technical feasibility and its experienced added value, although more pronounced for parents than professionals, merit further research into its effective implementation in the daily care practice of specific groups of patients that (temporarily) require frequent consultation across various organizational settings. In addition, the findings emphasize the need to further develop the technology through incorporating advanced consultation options by means of an integrated set of diverse system modules, next to increasing the system's ease of use and its integration in daily care practice.
Although a better definition of end users and further development of the technology are primary aspects to take into account when considering further implementation, a more comprehensive improvement strategy is needed to address the full range of communication gaps that were identified in this study. Critical aspects of organization of care (such as interdisciplinary guidelines and clear definition of roles) can be improved upon through development of protocols that specify commitments for collaboration and provide practical and detailed guidelines as a prerequisite for successful teamwork [5]. Such structures alone however do not

suffice to fundamentally change the practice of professionals and the way in which they collaborate [39]. In addition, organizing a process of collective learning would be required, in which professionals learn to understand each other's language and work practices and look at the care process from a network view instead of their own professional or organizational perspective [39]. This process might be guided by an action-research oriented approach, in which professionals from diverse settings share responsibility for specific project aims.

With respect to the methodology to evaluate patient care communication across integrated care settings like cerebral palsy, the mixed method approach worked as a "funnel" which proved to be useful to identify relevant gaps from both the perspective of parents as well as involved professionals. In addition to relevant quality frameworks we applied in this study [8, 13, 14], further research could focus on clarifying the role of patient care communication in realizing informational, relational and management continuity of care. Such knowledge could guide short and longer-term efforts to improve parent-professional and inter-professional communication in the care of children with special health care needs.

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Cerebral palsy is one of the most severe disabilities in childhood, which often makes strong demands on health, education and social services as well as on families and children themselves. In the Netherlands, children with cerebral palsy are the largest diagnostic group treated in paediatric rehabilitation, presenting care providers with heterogeneous and complex diagnostic and therapeutic challenges, which require specialized services from multiple professionals across various institutions and sectors. In order to provide 'integrated care' in these settings effective care coordination is essential, though in practice this is often challenged by inadequate communication among health care providers and organizations involved in the child's care.

The aim of the present thesis was to contribute to the improvement of patient care communication across the integrated care setting of children with cerebral palsy. Hereto, we followed two subsequent phases: 1) obtaining a better understanding of the experienced quality of patient care communication across the integrated care setting of cerebral palsy in three Dutch care regions; and 2) investigating the feasibility and usability of an eHealth application to improve patient care communication in these care regions.

With respect to the first objective, a literature search was performed for an adequate methodology to evaluate patient care communication in integrated care settings. We found that the majority of studies that evaluated patient care communication across organizational settings included only one aspect of communication (e.g. discharge- or referral communication), one communication link (e.g. general practitioner–hospital specialist) or one evaluation perspective (e.g. the perspective of primary care physicians). In addition, most studies relied on either quantitative- or qualitative methods, thus obtaining either general/ population based data, or in-depth qualitative data derived from small samples. In view of these shortcomings, we developed a mixed method evaluation approach attuned to integrated care settings, which we subsequently applied in three Dutch cerebral palsy care regions in order to identify experienced gaps in communication relevant to both parents and involved professionals.

With respect to the second objective, the identified gaps and needs of improvement were translated into functional specifications and technical requirements of an asynchronous secure web-based system for parent-professional and inter-professional communication, which was developed in an iterative design process and subsequently evaluated in a 6-months pilot in each care region. Despite the potential of eHealth to enhance access and increase efficiency, the actual uptake of eHealth technology is often lower than expected, which (among other factors) can be related to problems in user acceptance. One of the factors associated with lower user acceptance is the necessity to take into account the needs of users in the development and early innovation phases. Hereto, a staged approach of telemedicine can be applied, in which early prototypes are evaluated on technical stability and user acceptance, whereas the evaluation of more mature applications focuses on clinical- and cost-effectiveness. For the evaluation of user acceptance, it is important to gain insight in the determinants of use and non-use, which might facilitate the definition of user requirements and hence a better fit between user requirements and the system.

In Chapter 2 we describe the shortcomings of available methodology for the evaluation of patient care communication across integrated care settings, as well as the subsequent development of a three-step sequential mixed method evaluation approach, using the cerebral palsy care setting as illustration. The first step parent questionnaire aimed to identify those communication links in which parents experienced most quality gaps. Hereto, their expectancies and experiences with respect to parent–professional and inter-professional communication were compared. Resulting gaps formed the input of in-depth interviews with a subset of parents to evaluate underlying factors of ineffective communication, which subsequently formed the input of the final step's focus group meetings with involved professionals to corroborate and complete the findings. Dependent on the complexity of the studied care setting, the approach can be preceded by a network analysis to identify relevant communication links. As an objective method for this analysis a medical record review was proposed on the primary care provider's in- and outgoing cross-organizational correspondence.

In Chapter 3 the evaluation approach was applied to the integrated care setting of cerebral palsy in three Dutch care regions. The first step questionnaire showed that parents particularly experienced gaps in inter-professional- rather than parent-professional communication, particularly in the communication between the

(rehabilitation) hospital and the primary care setting. The second step's interviews showed that 60% of the experienced problems were related to organization of care (particularly lack of cooperation and patient-centeredness) and 40% to information exchange (particularly insufficient inter-professional contact and parents as messenger of information between professionals). In the last step's focus group meetings professionals recognized these gaps and primarily attributed them to organizational factors, such as capacity problems, lack of interdisciplinary guidelines and clear definition of roles, but also a certain hesitance for contact due to unfamiliarity with involved professionals in the care network.

In Chapter 4 the identified gaps and needs of improvement formed the basis of the development of an asynchronous secure web-based system for parent-professional and inter-professional communication. Its aims were three-fold: (i) to make communication more patient-centred; (ii) to facilitate inter-professional contact; and (iii) to increase network transparency. In this chapter we describe the system's design features, technical feasibility and clinical usability, as well as parents' and professionals' actual system use in a 6-month pilot in each of the three Dutch care regions. The system proved to be technically robust and reliable. Approximately two-thirds of the 30 parents and half of the 120 professionals used the system, of which most parents and some professionals reported to have experienced added value in its use, ranging from efficiency and accessibility to flexibility and transparency. Improvement suggestions were related to the system's ease of use and its integration into daily practice, as well as its fit with the target population.

As the 6-month pilot showed that half of the participating professionals had not used the system at all, and of those who had used the system one third had used it only once, the focus in Chapter 5 was on determinants of use and non-use of professionals. Hereto, we evaluated whether their system use was associated with their a priori expectancies and background characteristics, by comparing professionals who had not used the system (n=54) with those who had used the system more than once (n=46). In general, users had higher a priori expectancies than non-users. System use was associated with expected ease of use and time availability, i.e. more users than non-users expected that the system would be easy to use and that they would be able to reserve a time slot each week for responding to submitted questions. With respect to professionals' affiliation, system use was associated with professionals' institution and discipline, with more (para-) medical professionals among users and more education professionals among non-users. In addition, users represented more

patients than non-users. Remarkably, no association was found between system use and expected performance of the system.

In Chapter 6 we performed an in-depth evaluation of the system's contribution to parent-professional communication, as experienced by those parents who had used the system during the 6-month pilot. All users experienced a contribution of the system to parent-professional communication, although the extent of the experienced contribution varied considerably. The strength of the system appeared to lay in its contribution to sufficient contact, timely information exchange and accessibility, whereas consistency of information and the coordinator/ messenger role seemed less influenced by the system. In comparison with non-users, users had less positive baseline experiences with accessibility and a higher number of professionals in their child's care network. On the basis of this we hypothesized that the system might be particularly valuable for children with complex care networks and problematic access to professionals.

In the final chapter (Chapter 7) the presented findings in this thesis were integrated and discussed. It was concluded that the web-based system contributed to improvement of patient care communication across the cerebral palsy care setting, although the extent and nature of the experienced contribution varied considerably. Further research should focus on a better definition of end users as well as further development of the technology. Regarding the definition of end users, the system might be particularly valuable in younger age categories (early intervention period 0–4 years), in view of the frequent consultations required for montoring and diagnosis and the often rapidly changing network of (para-) medical professionals across diverse institutions. With respect to the further development of the technology, the focus should be on incorporating more advanced consultation options in the form of diverse system modules, which could be used separately or in combination with each other, dependent on the specific user needs. In addition the system's ease of use and its integration in daily care practice should be further optimized.
Overall, the findings in this thesis merit further exploration of the possibilities to provide web-based consultation as a (temporarily) additional service. This requires an interactive process of co-creation with intended users and stakeholders across diverse organizational and social contexts, which can serve other (paediatric) populations with special health care needs as well.

Cerebrale parese is een verzamelnaam voor een groep houdings- en bewegingsstoornissen als gevolg van een hersenbeschadiging rond de geboorte. Deze primair fysieke, maar vaak meervoudig complexe aandoening legt veelal een zwaar beslag op verschillende zorg-, onderwijs- en sociale voorzieningen en op de familie en het kind zelf. In Nederland vormen kinderen met cerebrale parese de grootste diagnostische groep die in de kinderrevalidatie wordt behandeld. Betrokken zorgverleners worden veelal geconfronteerd met heterogene en complexe diagnostische en therapeutische uitdagingen, die gespecialiseerde zorg vereisen van verschillende disciplines uit diverse instellingen en sectoren. Om in deze settings geïntegreerde zorg te kunnen verlenen is effectieve coördinatie noodzakelijk, echter in de praktijk wordt dit veelal bemoeilijkt door inadequate communicatie tussen de vele partijen die in de zorg rond het kind betrokken zijn.

Het doel van dit proefschrift is een bijdrage te leveren aan het verbeteren van deze 'transmurale' communicatie (i.e. communicatie 'over de muren van instellingen heen'), door (i) beter begrip te krijgen van de ervaren kwaliteit van de transmurale communicatie in de zorg rond kinderen met cerebrale parese in drie regio's in Nederland; en (ii) de haalbaarheid en bruikbaarheid van een 'eHealth' toepassing te onderzoeken als potentiële verbeterstrategie voor de transmurale communicatie in elk van de drie regio's.

Met betrekking tot het eerste doel van dit proefschrift is een literatuurstudie gedaan teneinde een adequate onderzoeksmethodologie te vinden voor de evaluatie van transmurale communicatie in geïntegreerde zorgsettings zoals cerebrale parese. Hieruit bleek dat de meerderheid van de studies die communicatie over verschillende organisatorische settings analyseerden, slechts één aspect van communicatie (bv. ontslag of verwijzing), één communicatie link (bv. huisarts - specialist) en/ of één evaluatie perspectief (bv. dat van eerstelijns professionals) in beschouwing namen. Ook maakten de gevonden studies veelal alleen gebruik van kwantitatieve- dan wel kwalitatieve methoden, waardoor ofwel relatief generieke/ populatie brede data werden verkregen, ofwel meer diepgaande gegevens op basis van kleine steekproeven. Gezien deze tekortkomingen is in het huidige onderzoek een sequentieel gemengde methode ontwikkeld voor de evaluatie van transmurale communicatie in geïntegreerde zorg settings.

Deze is vervolgens toegepast in de zorg rond cerebrale parese in drie regio's, teneinde ervaren knelpunten in de communicatie te identificeren die zowel voor ouders als betrokken professionals relevant waren.

Met het oog op het tweede doel van dit proefschrift, zijn de geïdentificeerde knelpunten en behoeftes aan verbetering uit de eerste onderzoeksfase vertaald naar functionele specificaties en technische vereisten van een beveiligde omgeving op het internet voor asynchrone communicatie tussen ouders en betrokken professionals en betrokken professionals onderling. Deze 'eHealth' toepassing is vervolgens ontwikkeld in een iteratief design proces en geëvalueerd in een pilot van 6 maanden in elk van de drie regio's. Ondanks de potentiële mogelijkheden van eHealth om de toegang tot- en efficiëntie van de zorg te vergroten, is het actuele gebruik van deze toepassingen vaak lager dan verwacht, wat (naast andere factoren) gerelateerd kan worden aan onvoldoende acceptatie van de beoogde toepassing door potentiële gebruikers. Voor een goede gebruikers acceptatie is het noodzakelijk om de behoeftes van potentiële gebruikers te betrekken in de vroege ontwikkeling en innovatie fases. Hiertoe kan een stapsgewijze benadering worden toegepast, waarin eerste prototypes geëvalueerd worden op basis van technische stabiliteit en gebruikers acceptatie, terwijl de evaluatie van meer uitgewerkte applicaties gericht is op klinische- en kosten effectiviteit. Voor de evaluatie van gebruikers acceptatie van de eerste prototypes is het van belang inzicht te krijgen in determinanten van wel of geen gebruik van de betreffende toepassing, aangezien op basis hiervan de definitie van gebruikers voorwaarden kan worden aangescherpt en aldus een betere aansluiting tussen de gebruikers en de betreffende toepassing kan worden gerealiseerd.

In Hoofdstuk 2 werden de tekortkomingen beschreven van beschikbare methoden voor de evaluatie van transmurale communicatie in geïntegreerde zorgsettings, alsook de hierop gebaseerde ontwikkeling van een driestaps gemengde methode evaluatie benadering, waarbij de zorg rond cerebrale parese als illustratie is gebruikt. De vragenlijst voor ouders (eerste stap) had als doel om die communicatie links te identificeren waarin ouders relatief de meeste knelpunten ervaren. Hiertoe werden hun verwachtingen en ervaringen vergeleken ten aanzien van de communicatie met betrokken professionals en de communicatie tussen betrokken professionals onderling. De hieruit resulterende communicatie links met knelpunten vormden de input voor diepte-interviews met een deel van de ouders (tweede stap), welke tot doel had de onderliggende factoren van de ineffectieve communicatie te inventariseren.

Deze onderliggende factoren vormden vervolgens de input voor focus groep bijeenkomsten met betrokken professionals (laatste stap) om de bevindingen te staven en te completeren. Afhankelijk van de complexiteit van de betreffende zorgsetting kan de driestaps evaluatie voorafgegaan worden door een netwerk analyse om relevante communicatie links in de betreffende setting te identificeren. Als objectieve methode hiervoor werd een dossieranalyse voorgesteld op basis van de schriftelijke transmurale correspondentie van die professional die de rol van primaire zorgverlener heeft.

In Hoofdstuk 3 werd de ontwikkelde driestaps evaluatie toegepast in de geïntegreerde setting van de zorg rond kinderen met cerebrale parese in elk van de drie regio's. Uit de vragenlijst kwam naar voren dat ouders met name knelpunten ervoeren in de onderlinge communicatie tussen professionals, met name in de communicatie tussen professionals in het ziekenhuis/ revalidatiecentrum en de eerstelijns praktijk. Uit de diepte-interviews bleek dat 60% van de ervaren knelpunten gerelateerd was aan organisatie van zorg aspecten (vooral gebrek aan samenwerking en patiëntgerichtheid) en 40% aan aspecten van informatie-uitwisseling (voornamelijk ontoereikend onderling contact tussen betrokken professionals waardoor ouders veelal de rol van boodschapper van informatie hadden). In de focusgroep bijeenkomsten werden deze knelpunten door betrokken professionals (h)erkend en voornamelijk toeschreven aan organisatorische factoren, zoals capaciteitsproblemen, gebrek aan interdisciplinaire richtlijnen en duidelijke definitie van taken, rollen en verantwoordelijkheden. Ook werd een zekere drempel voor onderling contact ervaren als gevolg van onbekendheid met betrokken professionals in het gehele netwerk rond het kind.

In Hoofdstuk 4 werden de geïdentificeerde knelpunten en behoeftes aan verbetering vertaald naar de ontwikkeling van een beveiligde internetomgeving voor asynchrone communicatie tussen ouders en betrokken professionals en betrokken professionals onderling. De doelstelling van het systeem was drieledig: (i) bijdragen aan een meer patiëntgerichte communicatie; (ii) faciliteren van onderling contact tussen betrokken professionals; (iii) vergroten van de transparantie van het zorgnetwerk. In dit hoofdstuk zijn de design specificaties, technische haalbaarheid en klinische bruikbaarheid van het systeem beschreven, alsook het daadwerkelijke gebruik van ouders en professionals in een pilot van 6 maanden in elk van de drie regio's. Het systeem bleek technisch stabiel en betrouwbaar. Bijna twee derde van de 30 ouders en de helft van de 120 professionals hadden het systeem gebruikt. Hiervan gaf de

meerderheid van de ouders en een derde van de professionals aan meerwaarde te hebben ervaren van het gebruik, variërend van efficiëntie en toegankelijkheid tot flexibiliteit en transparantie. De aangegeven suggesties voor verbetering waren gerelateerd aan gebruiksgemak, integratie van het systeem in de dagelijkse praktijk en de aansluiting van het systeem met de doelpopulatie.

Aangezien uit de pilot bleek dat de helft van de professionals het systeem niet gebruikt had en dat van hen die het systeem wel gebruikt hadden, een derde het slechts één keer had gebruikt, was Hoofdstuk 5 gericht op het verkrijgen van inzicht in determinanten van wel of geen gebruik van het systeem door professionals. Hiertoe werden professionals die het systeem niet gebruikt hadden (n=54) vergeleken met hen die het systeem meer dan één keer hadden gebruikt (n=46) ten aanzien van hun a priori verwachtingen van het systeem en hun achtergrond kenmerken. Over het algemeen hadden gebruikers hogere verwachtingen dan niet-gebruikers. Het gebruik bleek gerelateerd aan het verwachte gebruiksgemak en de verwachte beschikbaarheid van tijd: meer gebruikers dan niet-gebruikers verwachtten dat het systeem gemakkelijk in gebruik zou zijn en dat zij in staat zouden zijn om elke week de benodigde tijd te reserveren voor beantwoording van vragen. Hiernaast bleek het gebruik van het systeem gerelateerd aan de achtergrond van professionals, met meer (para-) medische professionals onder gebruikers en meer onderwijs professionals onder de niet-gebruikers. Ook bleken gebruikers meer kinderen te vertegenwoordigen in het systeem dan niet-gebruikers. Opvallend was dat er geen relatie werd gevonden tussen het gebruik van het systeem en de verwachte opbrengst ervan.

Het doel van Hoofdstuk 6 was inzicht te krijgen in de door ouders ervaren bijdrage van het systeem aan de communicatie met betrokken professionals, alsook welke factoren gerelateerd waren aan wel of geen gebruik van het systeem door ouders. Alle 21 ouders die het systeem hadden gebruikt, gaven aan een bijdrage van het systeem te hebben ervaren aan hun communicatie met één of meer betrokken professionals, hoewel de mate van de ervaren bijdrage sterk varieerde tussen de ouders. De kracht van het systeem leek te liggen in de ervaren bijdrage aan toereikend contact, tijdige informatie-uitwisseling en bereikbaarheid van professionals, terwijl het systeem minder invloed leek te hebben op het verkrijgen van eenduidige informatie en de rol van ouders als boodschapper van informatie en/ of coördinator van de zorg rond hun kind. In vergelijking met de niet-gebruikers, hadden ouders die het systeem wel hadden gebruikt voorafgaand aan de pilot minder positieve ervaringen met betrekking

tot de bereikbaarheid van betrokken professionals. Daarnaast hadden ouders die het systeem hadden gebruikt een groter aantal professionals in het zorgnetwerk rond hun kind dan de niet-gebruikers. Op basis hiervan werd als hypothese gesteld dat het systeem met name waardevol zou kunnen zijn bij kinderen met een complex zorgnetwerk waarin betrokken professionals moeilijk bereikbaar zijn.

In het laatste hoofdstuk (Hoofdstuk 7) zijn de bevindingen van de verschillende studies uit dit proefschrift geïntegreerd en bediscussieerd en op basis hiervan aanbevelingen voor vervolgonderzoek gedaan. Geconcludeerd werd dat het ontwikkelde communicatie systeem bij heeft gedragen aan verbetering van de transmurale communicatie in de zorg rond kinderen met cerebrale parese, hoewel de mate en de aard van de ervaren bijdrage sterk varieerde onder de deelnemende ouders en professionals. Nader onderzoek zou gericht moeten zijn op een betere definitie van eindgebruikers, alsook een verdere ontwikkeling van de technologie. Met betrekking tot de definitie van eindgebruikers werd aangegeven dat verdere implementatie van het systeem met name waardevol zou kunnen zijn in jongere leeftijdscategorieën (vroege interventie periode 0-4 jaar), gezien de frequente consultaties die dan nodig zijn voor het monitoren en diagnosticeren van het kind, in combinatie met het veelal snel veranderende zorgnetwerk van (para-) medische professionals uit diverse instellingen. Met betrekking tot de verdere ontwikkeling van de technologie werd geadviseerd om meer geavanceerde consultatie opties in te bouwen in de vorm van verschillende systeem modules, welke apart of in combinatie met elkaar gebruikt kunnen worden, afhankelijk van de specifieke behoeftes van de gebruiker. Daarnaast werd het belang benadrukt voor een verdere verbetering van het gebruiksgemak en de interoperabiliteit met de dagelijkse praktijk. Tenslotte werd aangegeven dat de bevindingen uit dit proefschrift vragen om een nadere exploratie van de mogelijkheden om internet consultatie als (tijdelijk) aanvullende dienstverlening aan te kunnen bieden. Dit vereist een interactief proces van cocreatie met beoogde eindgebruikers uit verschillende organisaties en sectoren, die vruchten af kan werpen voor diverse patiëntpopulaties met speciale zorgbehoeften.

Jitske Gulmans, geboren op 26 januari 1977 te Huissen, groeide op in Enschede. Nadat ze in 1995 aan het Ichthus College haar gymnasiumdiploma behaalde, begon zij met de studie Gezondheidswetenschappen aan de Universiteit Maastricht. Begin 2000 startte zij bij Roessingh Research & Development met haar afstudeeropdracht gericht op de evaluatie van een multidisciplinair behandelprogramma voor chronische pijn patiënten. Eind 2000 behaalde zij haar doctoraaldiploma, alsook een registratie als Epidemioloog A. In september 2002 trad zij als onderzoeker in dienst van Roessingh Research & Development en werd projectleider van het onderzoek CP Zorgketen, gericht op verbetering van de transmurale communicatie in de zorg rond kinderen met cerebrale parese in de regio's Enschede, Groningen en Amsterdam.

In september 2007 ging zij werken bij de Hanzehogeschool Groningen, waar zij als programmamanager betrokken was bij de opzet van Kenniscentrum CaRES, een netwerkorganisatie van vijf lectoraten gericht op het ontwikkelen van practice- en evidence-based kennis op het gebied van gezondheidszorg, rehabilitatie, onderwijs en sport. Sinds september 2009 is zij als docent werkzaam bij de Academie voor Sociale Studies in de bacheloropleidingen Maatschappelijk Werk & Dienstverlening en Sociaal Pedagogische Hulpverlening. Parallel hieraan werkte ze binnen een projectteam aan de ontwikkeling van de Master Social Work, een gezamenlijke masteropleiding van de Hanzehogeschool Groningen en de NHL Hogeschool te Leeuwarden. Deze opleiding is begin 2011 gestart en vanaf september is Jitske hierin kerndocent van de leerlijn Praktijkgericht Onderzoek. Naast haar onderwijswerkzaamheden heeft zij binnen het lectoraat Transparante Zorgverlening gewerkt aan de afronding van dit proefschrift, dat zij op 17 februari 2012 zal verdedigen aan de Universiteit Twente te Enschede.

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